"One step forward, one step backwards"

An Exploration of the Perception of Life of Adult People, as influenced by the Diagnosis of Severe and Enduring Anorexia Nervosa.

by

Laura Schut

A thesis submitted in partial fulfilment for the
requirements for the degree of Doctor at the
University of Central Lancashire

June 2019

University of Central Lancashire

STUDENT DECLARATION

Concurrent registration for two or more academic awards

I declare that while registered as a candidate for the research degree, I have not been a registered candidate or enrolled student for another award of the University or other academic or professional institution

Material submitted for another award

I declare that no material contained in the thesis has been used in any other submission for an academic award and is solely my own work

Signature of Candidate

Type of Award **Professional doctorate**

School **School of Nursing**

Abstract

Title: “One step forward, one step backwards’. An exploration of the perception of life of adult people, as influenced by the diagnosis of severe and enduring anorexia nervosa.

Aim: The aim of this study is to generate an in-depth understanding of the phenomenon regarding the ‘the experiences of life’ as influenced by the symptoms of severe and enduring anorexia nervosa.

Background: In the Netherlands, current treatment programmes for eating disorders mainly focus on the physical and psychological recovery of patients with acute anorexia nervosa. However, treatment interventions focussing on those with shorter illness trajectories may not be appropriate for those with severe and enduring anorexia nervosa (SE-AN) (Touyz et al., 2013), since short-term treatment seems to have a minimal effect on persistent issues pertaining to weight, food and body shape (Touyz et al., 2013). It is precisely these beliefs that are inextricably linked to SE-AN. Hence, health care professionals identify the need for non-specific medical palliative care for patients with SE-AN. It seems reasonable, therefore, to suggest that the complexity of the condition as a severe and chronic disorder requires a different treatment paradigm (Tierney & Fox, 2009; Touyz et al., 2013; Touyz & Hay, 2015). Thus, full recovery from every manifestation of SE-AN should perhaps not be the primary goal of treatment for individuals with SE-AN. Instead, the focus should be on improving the quality of life and avoiding failure experiences in treatment that further discourage patients (Touyz & Hay, 2015).

Method & Methodology: The Constructivist Grounded Theory approach focuses on the experienced quality of life for people diagnosed with SE-AN (Charmaz, 2006, 2008, 2010). In this study, eight women were interviewed, adhering to the guidelines of Charmaz’s approach.

The data was then analysed employing the Constant Comparative Method, with the support of the software program, MAXQDA.

Findings: Twelve key aspects were revealed within four theoretical categories, which were: ‘Suffering, but not in silence’; ‘One step forward, one step backwards’; ‘Connective tissue’; and ‘Best friend, best enemy’.

Contribution to the current knowledge: Four key messages are described concerning the current findings and which contribute to a deeper understanding of the social processes of people with SE-AN, which are seen as responsible for the experienced quality of life. The findings are considered as being a logical result of the research process. Firstly, Key Message One: ‘Recognising suffering as a continual additional effect in the approach of people with SE-AN’ is presented, which suggests active changes in the behaviour of professionals. Key Message Two proposes the ‘Validation of the cyclical process of ‘adaptation versus rejection’ of the anorexia nervosa status’. This message suggests offering psycho-education which refers to the Developmental Model of Chronicity with the aim of improving of the quality of life experiences. Furthermore, it also encourages patients in the establishment of daily routines with regards to contacts and hobbies, perhaps even with the assistance of an assistance dog. To help achieve this, professionals should plan regular meetings with the SE-AN sufferer’s family and other important people in their lives in terms of the education of the chronicity and to support them in the acceptance of SE-AN in their loved ones. Key Message Three presents the following stance: ‘Recognising the impact of, and respecting the communication through the SE-AN condition’. This refers to recognising the need for customised psycho-education, accommodating the SE-AN approach for *all* people involved, including the healthcare professionals, such as nurses, psychiatrists, general practitioners and others. Moreover, it meets the individual criteria of being specific and respects the shared decision-making approach.

Finally, Key Message Four presents the ‘Respectful approach of the request for attendance and help, in the attention of an adjusted paradigm’. The data which emerged explicitly identifies the need for unconditional access to professionals for people with SE-AN, without imposing an impossible regime on them regarding their SE-AN condition, which refers to the demand for an adjusted treatment paradigm.

Contents

List of Flowcharts

List of Figures

List of Memos

List of Tables

List of Key Findings

Acknowledgements

One of the substantial components of the thesis deserves a prominent place right at the start of this work. Firstly, I would like to thank the most important people of this research. Thank you to all the participants, for your confidence, loyalty and openness. Without you, I could not have accomplished this work.

To my loved ones, Toon, Cosmo, Naomi, Kayun, Chet and Nina, thank you for your incredible support, love and patience, and lots of time spent walking the dogs and doing the dishes. It must have been hard, I know, and I promise not to study anymore, no way… except for taking a course learning how to play the banjo.

To my father Jelle, Annelies, Monica and Daniel, I want to thank you so much for your support and personal interest.

To my supervisors, Karen Wright, Jean Duckworth and Peter van der Graaff, you are all the greatest, and without your devotion, knowledge and insights, I could not have made it through this journey. You all supported me by being a practical and philosophical mirror. You all believed in me, and I am so thankful for that. And Karen, your moral support made me cry with the relief I experienced, when the study almost consumed me. I thank you so much.

To Vikki Hulse, thank you so much for your hard work on the language.

To all my team members and the ‘Captain’, Michaela Vlot, thank you all for your belief in me, and for your moral support. You all made my study possible.

To Sebastian Cardona, Ellis Trompetter, Paul Cüsters, Marti de Jong, Jaqueline Okkes and Wijbrand Hoek, Iris van der Meer and Marc Godschalk, I thank you all for your moral support.

To Maryella Grootjans, ‘and suddenly there are no impossibilities anymore’. I owe you!

To the board of Emergis, Paul de Schipper en Gerco Blok, they made it possible to believe in myself, I thank you for that.

To my study companions, Sandra van Duijn & Sandra de Wit, Wilma van der Vlegel, Ferdy Pluck, Falco Jansen, and my Dutch teachers at the Hogeschool Utrecht: Marlou de Kuiper, MSc, dr. Anneke de Jong, dr. Roelof Ettema, dr. Paul Breman. I thank you all for preparing me to conduct a doctorate. Marlou, ‘I often killed my darlings’.

And finally to Marieke van de Geer and to all my nurse specialist colleagues of Emergis, thank you so much for your support!

I dedicate this thesis to my friend Erik Jansen, ‘die rooie’. I am sure that he is so proud of me.

Abbreviations

AN	Anorexia Nervosa
BMI	Body Mass Index
DSM-5	Diagnostic and Statistic Manual of Mental Disorders (5th edition)
ED	Eating Disorder(s)
EBP	Evidence-Based Practice
GT	Grounded Theory
GP	General Practitioner
Manp	Master advanced nursing practitioner
NICE	National Institute for Health and Care Excellence
QoL	Quality of Life
SE-AN	Severe and Enduring Anorexia Nervosa
SEDU	Specialist Eating Disorder Unit(s)

Reader's guide

Before starting this thesis, I will provide an explanation for my choice of writing style, the use of the specific terminology of the medical and psychiatric environment and the method of interpreting quotations.

In this thesis, I have written in the first person for a several reasons. Firstly, by writing in the first person, I avoid anonymizing my occasional personal situation. Furthermore, in this study, I have used Constructivism (Charmaz, 2006), a philosophical stance built on the perspective of the participants in this particular field and my own perspective as a nurse, as a researcher and as a female. Within Constructivism, I was encouraged to reflect on my actions, reactions, thoughts, the theoretical frames that I use in my daily work, the knowledge and personal experiences associated with the topic of the research and my role as a nurse therapist.

Despite the fact that I sometimes use specific terminology from the medical and psychiatric environment, in my writing, I attempted to use sentences that are common for nurses and other care workers, relevant to the therapeutic alliance for people with eating disorders. Furthermore, I chose to illuminate a specific form of an eating disorder: the severe and enduring form of Anorexia Nervosa (SE-AN), in the context of *'the quality of life'* in order to improve the therapeutical alliance of this group. Hence, I use words, such as *'patients', 'people with SE-AN', 'SE-AN women', 'women SE-AN sufferers',* or simply *'the women'* to interpret the topic of interest. I do not wish to offend anyone by the use of these terms. The women participants are identified by a 'pseudonym', names chosen by the participants themselves.

Finally, I use *italics* to paraphrase quotations and definitions from literature sources, and also use *italics* in key findings, in order to make the words notable. In addition, direct references and the pronunciations of the participants are shown in the Apple Chancery font for clarity.

Publications arising from this project

Schut, L. (2018). Langdurige en ernstige anorexia nervosa. *Nurse Academy GGZ*. 3: pp 47-52.

Chapter 1 Introduction

In this, the first chapter of my thesis, I will provide my motivations for the study and some background to the subject of the study, related to my personal and professional perspectives and supported by academic rationale.

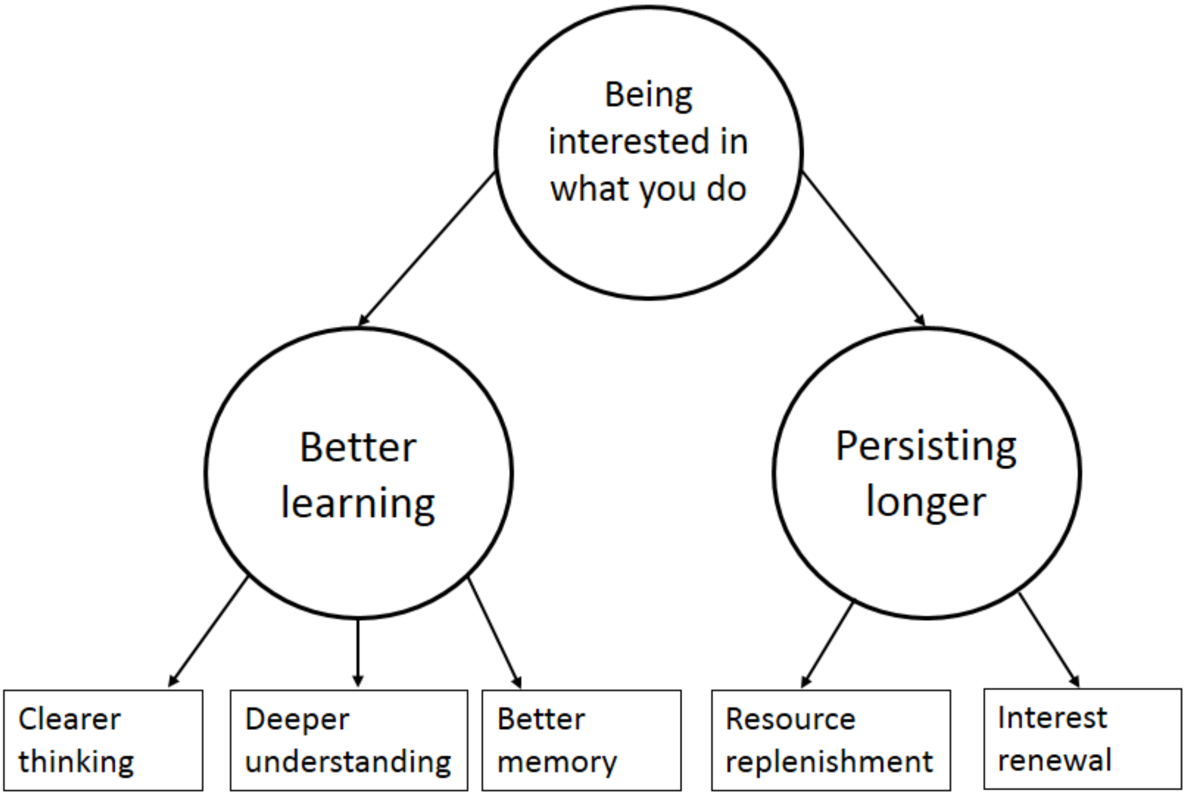
I have adopted Grounded Theory (GT) for this study (Glaser & Straus, 1967; Strauss & Corbin, 1998; Charmaz, 2006). By using GT, I am able to develop a deeper understanding of the quality of life of people who suffer from Severe and Enduring Anorexia Nervosa (SE-AN). Anorexia Nervosa (AN) is a serious psychiatric disorder, and people who suffer from AN may develop serious psychological, physical, and social complaints (Hay et al., 2014; Dutch Guidelines Eating Disorders, 2017). It is my intention to identify and highlight the effects of chronic Anorexia Nervosa on individuals receiving treatment at a specialised unit for eating disorders (SEDU) in a mental health unit in the Netherlands. In the first chapter, I will give the reader an overview of my research, and explain the significance of this study.

1.1 History of the study

Charmaz (2006) uses Constructivism as a philosophical insight and, therefore, I will explain my personal background, interests and motivations related to the topic. In answering an important question to myself, "*Why do I want to do research on people with Severe and Enduring Anorexia Nervosa?",* I have presented an academic rationale and underpinned this with both a personal and a professional interest. I hope to find a deeper level of understanding regarding the phenomenon of the 'severe and enduring suffering caused by Anorexia Nervosa', as well as its effects on the experienced 'quality of life'. As a starting point, I have drawn on my own personal interests.

The project is supported by the use of the Process-Focussed Approach by Visser (2014) (Flowchart 1). Visser (2014) refers to the Theory of Resource *Replenishment* according to Thoman et al. (2011). The Flowchart 1.1 below (Visser, 2014) illustrates the Theory of the Process-Focussed Approach. Visser (2014) states that if we dive into something that really interests us, we can find ourselves in a psychological state of 'attentive involvement' and we experience positive emotions. With these conditions, we can think more vividly, develop a deeper understanding of the material we are interested in, and we have a better recollection of the topic of interest. As a result, we are adaptive learn better and more efficiently.

> *"While we are working hard on something, which interests us, we are gaining energy"*
> (Visser, 2013: p 20).



Flowchart 1: The Process-Focussed Approach (Visser, 2014: p 19)

1.1.2 Motivations for the study

In this section, I elaborate on my personal and professional motivations, and the academic rationale for the study, and I consider this in light of the current and existing knowledge of the subject of study.

1.1.3 Personal motivations

Thirty years ago, I started working in a specialist eating disorder service as a registered mental health nurse. It was the only specialist eating disorder programme in the Netherlands in the late 1980s, and somehow, though I did not know why, I felt compelled to work there. Working in the service was very different to the usual psychiatric wards. It impressed me that the patients, mostly young women, were motivated to take part in the treatment programmes. The atmosphere was emotionally secure; the patients were friendly, almost as though they had known each other for a long time; and there was no aggression, unlike other services that I had known. Furthermore, all the patients had a Body Mass Index[1] (BMI) of 15 or higher. As naïve and inexperienced as I was at the time, I thought that a BMI of 15 was the lowest measurement that people could reach.

After some time spent in other hospitals, I returned to the same specialised programme, in the interim, developing into a more experienced practitioner, and I began to recognise the lonely fight that patients had with their eating disorder. At that time, the criterion of the minimum BMI before getting help had not been introduced. Here, I recall taking care of an especially thin young woman. One day, which was the so-called 'weight day', she put clay in her underwear in order to appear heavier on the scales. I felt so sad and awkward when I discovered the 'trick'. The young woman burst into tears, told me she felt ashamed of her behaviour, and she explained to me her personal fight and the anxiety she experienced, along with the fear she had of being sent away. Then, one weekend, when she had permission to take a leave of absence from the hospital, she passed away.

Nowadays, I practice in an eating disorder service as a nurse practitioner[2]. One part of my job is screening new patients and reporting on their biographic history, which mostly comprises a

---

[1] BMI: Body Mass Index = KG/M^2

[2] In the UK, a similar role is referred to as a 'Specialist Nurse Practitioner'

personal history of their long-term illness. As a nurse therapist, I treat people who have been ill for some considerable time. These people often possess (sometimes) heartbreakingly long histories of illness and distress, interspersed with a poor quality of life, full of anxiety.

It is precisely these stories which have triggered me into developing a special interest for people who are suffering from chronic AN. In this study, I focus on females only.[3] Hence, as a female researcher utilising Constructivism, which I use as the philosophical foundation of this Grounded Theory study, so, I am obliged to take account of my own view on the world, through a female lens.

1.1.4 Professional motivations

A few years ago, I was inspired to combine clinical practice with the academic world, and I became a nurse practitioner, specialising in mental health. A mental health nurse practitioner (NP) in the Netherlands specialises in the screening, management, and relapse prevention of (mental) health conditions, as seen from the perspective of the psychiatric patient and their environment (as per the *Diagnostic and Statistical Manual of Mental Disorders-5,* DSM-5) (VENVN.nl, 2012). In the Netherlands, in the field of eating disorders, a NP specialising in mental health can act as the primary health practitioner for those individuals experiencing a chronic disease. This professional position affords me the privilege of day-to-day contact with the people whose experience I have researched. It is my hope that this will positively influence my practice and the practice of others, due to the insight that is gained through this study.

1.1.5 Academic rationale of the study

Anorexia is a severe psychiatric condition. Consistently, low levels of motivation to change, a negative self-image, and a disease-focused life-style are therapeutic challenges in people with a chronic disease (Touyz et al., 2013). Furthermore, treatments that focus on the full recovery

---

[3] See also Section 2.1.2: The prevalence and incidence of AN, and Section 2.2.4: The quality of life as seen in the context of a feministic perspective.

of psychological and physical complaints in patients with severe and enduring Anorexia Nervosa (SE-AN) have led to a high drop-out rate for therapeutic alliances (Wonderlich et al., 2012). It has also been claimed that AN has the highest mortality rate of any mental illness (Steinhausen, 2002; Harbottle et al., 2008). Despite these assertions, an appropriate treatment for SE-AN patients is little represented in scientific guidelines for the treatment of eating disorders, although researchers do note the existence of these patients (Steinhausen, 2002; Harbottle et al., 2008; Wonderlich et al., 2012; Touyz et al., 2013). For example, the *National Institute for Health and Care Excellence Guidelines for eating disorders* (NICE) (2017) do not acknowledge the extended recommendations for the treatment of SE-AN. This oversight may lead to treatment goals that are unclear and unfocused, and which can increase the demotivation of patients (Touyz et al., 2013).

There is a significant amount of academic research into the eating disorder population, but little that considers the quality of life in people with SE-AN. Hence, I believe that this study fills a gap in the knowledge and in the academic literature. In the next section, I provide a brief summary of each chapter.

1.2 Contents of chapters

In the second chapter, I give an explanation of the background of this study. Therefore, I present the prevalence and incidence rates of AN, definitions of AN, and the current diagnostic standard as used in Specialist Eating Disorder Units (SEDU) in the Netherlands. In addition, I provide the definition of the severe and enduring form of Anorexia Nervosa, definitions of the quality of life and a brief description of the daily practice in the SEDUs in the Netherlands. Furthermore, I present the development of the methodology and, in addition, the rationale for using a qualitative approach in this study is discussed, along with the philosophical insights. A feministic perspective will frame the study. Finally, I enlighten the research question, and the aim and objectives will be presented.

In Chapter Three, I give special attention to the timing of the literature review, since there is an on-going discussion about *when* to conduct this component of the research. In this chapter, I explain my decision to place the literature review at the end of my project. Furthermore, I present the methodology by adopting a qualitative constructivist Grounded Theory (GT), as described by Charmaz (2006), which is fundamental for this research. The similarities and differences between the insights of Glaser & Strauss (1967) versus the constructivist approach will be discussed, as well as the philosophical insights of the qualitative method referring to the ontology, the epistemology and the theoretical perspective, which all support the philosophical insights of Constructivism. Finally, I define ‘feminism’, and with this, I elaborate on the importance of the feministic features of this project, and thus, my choice of the use of the feministic insights, which occurred in the data presented.

In Chapter Four, I describe the method of recruitment and the sampling of the women who were to become the study participants of this project. The fundamental methodological steps according to Charmaz (2006) will then be discussed, starting with a formal definition of a Constructivist Grounded Theory approach, followed by a brief explanation as to the importance of the use of the strategies as developed for a GT method for this study. Hence, I will outline each fundamental methodological step in the data processing. Finally, I will explain the choice of using the software programs, MAXQDA and Simple Mind Lite in the process of the data analysis.

In Chapter Five, I elaborate on the reliability of this study. I will explain the study’s credibility in general, in terms of a qualitative research method and according to the constructivist GT of Charmaz (2006). Furthermore, particular attention will be paid to the concepts of reliability and validity (Guba, 1981; Chiovitti & Piran, 2003; Coony, 2011), in order to strengthen the findings of this study. These concepts are highly relevant to the method as used by Charmaz (2006, 2008). Finally, the concept of bias will be examined, and in addition, ethical considerations, confidentiality, anonymity and funding/sponsorship will be discussed.

In Chapter Six, I identify and present the SE-AN women's experiences and reveal their social processes. Within the constructivist method, I apply transparency in order to reinforce the credibility of the study, whilst maintaining rigorous standards of GT as described (Chiovitti & Piran, 2003; Charmaz, 2006, 2008; Coony, 2011). In this phase of the study, the rigour is retrieved in the credibility by using the actual words of the women, by maintaining a personal journal and memo writing. In this study the women act as guides for the project (Chiovitti & Piran, 2003; Charmaz, 2006, 2010). Thus, using several methods are essential to ensure the credibility of the Grounded Theory in order to maintain the rigour of the GT method (Coony, 2011; Charmaz, 2006).

Chapter Seven elaborates on the development of the theoretical categories. A constructivist approach aims to present a cohesive and logical theoretical rendering by those who describe and explicate the experience of the phenomenon (Charmaz, 2006). The first theoretical category which is presented is 'suffering, but not in silence'. This theoretical category suggests multiple instances of suffering within the SE-AN condition. Conversely, the suffering itself can act as a means to communicate the suffering. To give an explanation of this category, I presented an exploration of the theoretical findings, which appeared during the focused coding process. These findings explicitly give meaning to the construct of suffering in people with SE-AN.

In Chapter Eight, the findings are presented with reference to the theoretical significance of the category, 'one step forwards, one step backwards'. As in the previous chapter, I used similar methods to reveal the relevant data in order to define the properties of this main category. The methods used provided insights in to the subsequent steps, such as framing the properties and elaborating on the properties by exploring the dimensions. Finally, a conclusion is presented, wherein all the findings are fractured back together to give a general insight into the main category.

Chapter Nine presents the findings of the theoretical category, ‘connective tissue’. Similar methods to reveal the relevant data were also conducted. The theoretical category of ‘connective tissue’ emerged as the third theoretical category of this study. Related study findings were explored whereby ‘communication’ through the AN condition to human contact’ of SE-AN women emerged.

People with SE-AN made use of various experiences to make meaning from their interactions to define and justify their interpretation of the suffering from SE-AN. The theoretical category of ‘connective tissue’ masters several properties of the SE-AN women and their societal environment. The subcategories fostered a number of theoretical findings, which function as an underpinning of the theoretical category.

In the final data analysis chapter, as detailed in Chapter Ten, the findings of the fourth theoretical category, ‘best friend, best enemy’ are presented. This category indicated the extant ‘tension’ between the opposites, namely, *acceptance of the SE-AN status* versus *the perspective of recovery*. Similar methods in the data gathering and analysis were used to reveal relevant findings in administering grounded data.

The theoretical category of ‘best friend, best enemy’ emerged as the fourth most important domain in this study. As in the previous chapters demonstrating the findings, several appropriate techniques were used to reveal the relevant data. Finally, the properties and their dimensions were explored in separate paragraphs, whereby the properties were supportive of the emerging theoretical and initial codings. The initial codings made the data grounded and, thus, empirical.

In Chapter Eleven, the twelve key aspects (as detailed in the four theoretical categories) and which emerged in Chapters 7, 8, 9 and 10 are explored. These key aspects have been presented by placing, defending and comparing them with additional findings from the literature. With this, an increasing understanding of the quality of life for people with SE-AN is realised. In general, the project findings created a deeper understanding of the social processes, which occurred in those with SE-AN, and also an insight into how they engage with others. The four categories and their key findings, as identified in the previous chapters, provided a new step forward in the understanding of the subtle social processes that shape the actions of those who experience SE-AN in societal interaction and how these can best be understood.

In Chapter Twelve, I focus on the outcomes of the project, related to the four key concepts: ‘suffering, but not in silence’; ‘one step forward, one step backwards’; ‘connective tissue’; and ‘best friend, best enemy’. Together, they provided the behaviours in the interaction with relatives and friends, professionals and other societal contacts. The revealed key findings validated the interpretation of the influences on their lived quality of life. Moreover, during the data analysis, key messages emerged which may be proposed as potential solutions to these four categories. The chapter then examines the strengths and limitations of the study, and this is then followed by a final and general thesis conclusion.

In Chapter Thirteen, I examine my personal position as a researcher in conducting this study project. Hence, I elaborate on the reflexivity and the importance of this regarding a constructivist GT approach.

1.3 Summary

In this first chapter, I have given a brief introduction of myself, my personal and professional interests and my motivations for the study, in order to substantiate my interests in the topic of this research. Furthermore, I have also provided a brief summary of the contents of the various chapters.

Chapter 2 Background

2.1 Introduction

To enable the understanding of the phenomenon of a diminished quality of life in people who suffer from severe and enduring anorexia nervosa, I define the three major elements in this study:

- severe and enduring anorexia nervosa;
- quality of Life;
- specialised eating disorders units (SEDU).

In the current chapter, I define AN, as described in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (2017). In addition, I highlight that a reduced quality of life is evident in those suffering from severe and enduring anorexia nervosa, and provide background information regarding the state of current treatment programmes for eating disorders.

2.1.2 The prevalence and incidence of Anorexia Nervosa

According to the Royal Australian and New Zealand Guidelines for the treatment of eating disorders (2014), AN is not solely a female disorder in Western countries. Typically, the lifetime prevalence of AN occurs in approximately 1% of the female population and in 0.5% of the male population (Hay et al., 2014). Various studies estimate the annual incidence of females diagnosed with AN varies from 14 per 100,000 per year up to 50.9 per 100,000 per year, and for males, the figure is 2 per 100,000 per year (Pawluck & Gorey, 1998). Furthermore, a Dutch meta-analysis by Smink et al. (2012), examining the aetiology, prevalence and incidence of eating disorders, claims that the overall incidence rate of AN in the Dutch population remained stable, when comparing two time periods. Between 1995 and 1999, the figure was 7.7 per 100,000 people, and between 1985 and 1989, it was 7.4 per 100,000 people.

Anorexia is a severe psychiatric disorder. Consistently, previous studies have claimed a mortality rate of between 10% and 15% (Harris & Barraclough, 1998; Roux et al., 2013; Keshaviah et al., 2014; Brown & Mehler, 2015). Anorexia may, therefore, have the highest mortality rate of any mental illness (Steinhausen, 2002; Harbottle et al., 2008). Some 45% of all patients with AN are reported to recover partially (Steinhausen, 2002; Harbottle et al., 2008). However, 30% of the group who partially recover continue to report severe complaints with regards to the AN condition, and there is evidence to suggest that up to 25% relapse and develop the severe and enduring form of Anorexia Nervosa (SE-AN) (Steinhausen, 2002; Thornton et.al., 2016).

2.1.3 A definition

Although AN is much more than a clinical diagnosis, in healthcare services in the Netherlands[4], the terms Anorexia Nervosa, Anorexia, AN, or simply *Ana*, (as a first name) are commonly used. In the search for a definition of AN, there is an overwhelming amount of information on the internet, on bookshelves, and in (female) magazines. Sometimes, definitions are seen from one specific point of view, as shortly described, or they are altered to fit their (young) audience. An example of this is found on Proud2Bme.nl[5]:

> *People with Anorexia Nervosa are afraid of becoming fat, whilst they objectively are too skinny (underweight). Their daily life is all about food and weight. After the eating moments they try to decrease the effects of calories by exercising intensively, and/or vomiting or using laxatives. Also binge eating may occur. Anorexia Nervosa is much more common in women than in men.*
> (Proud2Bme.nl, 2009*).*

As a further illustration, a quotation from an anonymous patient is described below in the lecture by van Furth (2013):

> *I want to be so light that when I walk through the snow, I leave no footprint*
> (Van Furth, 2013: p 3).

---

[4] ‘Ana’ is used more frequently in the Netherlands. I accept that this is less popular in the UK.

[5] Proud2Bme: A Dutch self-help site, supported by the NAE, (Nederlandse Academie Eetstoornissen) Dutch Academy for Eating Disorders.

The literal meaning of Anorexia Nervosa, translated from Greek, means ‘A lack of appetite, provoked by neurotic causes (Vandereycken, 2006). Although this definition is not strictly accurate, an anorexic patient usually ignores or tries to resist feelings of hunger. Suppressing feelings of hunger arise from an intense dislike and fear of becoming obese. This process eventually leads to emaciation. Thus, Anorexia Nervosa can best be understood as “an urge for thinness” (Vandereycken, 2000: p 314).

A definition found in a handbook of psychiatric nurse care (Townsend, 2009) defines the impact of the eating disorder on the quality of life as follows:

> *Anorexia Nervosa is a clinical syndrome whereby the person experiences an intense fear of gaining weight. It is characterised by a severe distortion of the body image, preoccupation of food and a refusal to eat. The disorder usually appears in women and girls at the age of twelve and thirty years. Without interventions, a patient may not survive the illness.*
>
> (Townsend, 2009: p 207)

2.1.4 Diagnosis of Anorexia Nervosa according to the DSM-5

In terms of psychiatric handbooks, most writers refer to the description of AN according to the DSM-5. Furthermore, in the Netherlands, it has been determined that from 1 January 2017, regular healthcare providers should make use of the DSM-5 as a diagnostic method. The Minister of Health, Welfare and Sports[6] requires the use of the DSM-5, otherwise, health insurance companies do not reimburse for the cost of treatment. According to the DSM-5 (2014), AN is described in the following table (1):

---

[6] https://www.rijksoverheid.nl/documenten/kamerstukken/2016/01/15/kamerbrief-over-herziening-advies-zorginstituut-over-dsm-5)

Table 1: Diagnosis of Anorexia Nervosa according to the DSM-5 (2014: pp 278-279)

Anorexia Nervosa: 307.1 (F50.01 or F50.02)
1. Restriction of energy intake relative to requirements leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected. 2. Intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.
Specify if: In partial remission: After full criteria for anorexia nervosa were previously met, Criterion A has not been met for a sustained period, but either Criterion B or C is still met. In full remission: After full criteria for anorexia nervosa were previously met, none of the criteria have been met for a sustained period of time.
Specify current severity: The minimum level of severity is based, for adults, on current body mass index (BMI) (see below) or for children and adolescents, on BMI percentile. The ranges below are derived from World Health Organization categories for thinness in adults; for children and adolescents, corresponding BMI percentiles should be used. The level of severity may be increased to reflect clinical symptoms, the degree of functional disability, and the need for supervision. Mild: BMI > 17 kg/m Moderate: BMI 16-16.99 kg/m Severe: BMI 15-15.99 kg/m Extreme: BMI < 15 kg/m

2.1.5 Severe and Enduring Anorexia Nervosa

In Section 2.1.3, I defined AN according to various definitions (Proud2Bme.nl (2009); Vandereycken (2000); Townsend (2009) and the DSM-5. In the current section, I elaborate on the ‘Severe and Enduring’ form of AN.

Although there is no consensus on the thresholds regarding the severity and chronicity of the condition, a study by Bamford & Mountford (2012), focusing on the chronic form of AN, suggests the following diagnostic criteria: 1) continuously ill for 10 years or more; 2) at least one therapeutic treatment by a recognised professional; 3) clearly reduced quality in a number of life-domains; 4) constant demonstration of low motivation for recovery. Strober et al. (1997) argue that a course of anorexia of 10 years or longer is more difficult to treat. A further study of SE-AN, by Touyz et al. (2013), used a criterion based on the duration of anorexia for 7 years or longer. Subsequently, a qualitative study by Robinson (2015) used the term ‘Severe and Enduring Eating Disorders – Anorexia Nervosa’ (SEED-AN). This term was selected as the study did not want to exclude other forms of chronic eating disorders based on other criteria. Robinson (2015) investigated the phenomenon of chronic anorexia with a duration of 20 years or longer, in order to better understand the extremes in symptomatology and the adaptation of the disease. In this study, I decided to focus on participants who had suffered the disease for 7 years or longer, and I use the term SE-AN, since I only focus on the phenomenon of the severe and enduring form of AN.

SE-AN is associated with a diminished quality of life (Touyz et al., 2013). Patients may develop psychological complaints, such as depression, anxiety, concentration and memory problems, and obsessive thoughts that centre on food, weight, and body image (Tchanturia, 2014). The chronic malnutrition associated with Anorexia Nervosa can also lead to serious neuropsychological and physical dysfunction (Arkell & Robinson, 2008; Robinson, 2009; Birmingham & Treasure, 2010; Wonderlich et al., 2012). Equally, the effects of physical complications can lead to multiple severe physical health problems in SE-AN patients. For example, the purging type of Anorexia Nervosa can irritate the bowels (Culkin et al*.,* 2012; Neychev & Borruso, 2015) and also the oesophagus (Benini et al., 2012). In addition, it is also associated with weakened dental enamel (Wentz et al*.,* 2012), enlarged parotid glands, and altered electrolyte levels (Parkash et al., 2014). In turn, these can lead to life-threatening cardiac arrhythmias and renal dysfunction (Tenwolde, 2002).

Living with SE-AN has a significant negative impact on the social life of a person, and patients can be perceived as a burden to their families and caregivers (Treasure et al., 2001; Strober, 2004; Striegel-Moore, 2008; Touyz et al., 2013). Santonastaso (1999) also suggested that SE-

AN is associated with both subjective and objective burden, as well as over-involvement with and the existence of psychiatric symptoms in the key relatives of people with AN. In addition, patients often cannot manage their work or study commitments, and this can also be associated with social isolation (Touyz et al., 2013). Patients become dissatisfied in various areas of their lives, including health, sexuality, finances, leisure activities, and social status (Noordenbos, 2010). Thus, some patients are likely to lead a life with a condition that is both socially and physically disabling (Noordenbos, 2010). This is exemplified in the words of Sandy [7] below:

"Dear friends,
No one failed to notice that my health is getting worse, despite my attempts to feel better in all sorts of ways. Sometimes I seem to have found the solution, but 10 steps forward always seems to end up in 20 steps back.
Last week, I was, once again, urgently hospitalised with a weight of 25 kg, a potassium deficiency and a heart-rhythm disorder.
After showing I was 'energised', I, again, went home. I am finished with my treatment, I am chronically ill."

(January 2017, quotation from Sandy, permission to publish has been given)

2.2 Quality of Life

Studies refer to a diminished quality of life (de la Rie et al., 2005; Noordenbos et al., 2000; Noordenbos, 2010; Touyz et al., 2013). In order to define the 'quality of life', a broad literature search was conducted. To this end, I have used (a personal collection of) books and the internet, with the following databases being used: Google Scholar, Google, Pubmed, Psycharticles, EBSCO, and Cochrane, in order to examine the defining characteristics of 'quality of life'. Below are the definitions applicable to the context of people with Anorexia Nervosa.

---

[7] A pseudonym is given for reasons of confidentiality.

2.2.1 In search of a definition of 'Quality of Life'

The search for a definition for 'quality of life' (QoL) is challenging. As seen from a historical perspective, Pigou (1920), an English economist, introduced the term and connected it to the prosperity index (Pigou, 1920: Ch. 1). Although it is clear that economic circumstances help to determine the concept of 'quality of life', subjective factors were ignored in this approach.

In the 1980s, the term 'quality of life' was introduced in the field of medicine. In the approach of Bruyninckx & Mortelmans (1999), the four paradigms of the health sciences, according to Lafaille (1993), were refined. The first paradigm, the *biomedical paradigm*, the oldest paradigm in terms of the concepts of healthcare, has positivistic and reductionist characteristics. It refers to a definition of an illness as a biological discrepancy (Bruyninckx & Mortelmans, 1999), whereby the disturbance is strictly an issue of the human body. Rattcliffe (1993) gave a reaction to this narrow definition, which was described in the study by Bruyninckx & Mortelmans (1999), in order to provide a more realistic view on health and disease. Bruyninckx & Mortelmans (1999) argue that Rattcliffe (1993) supports the psychological and physical 'whole' of the human being. Secondly, the basics of the *system paradigm,* mainly supported by Gregory Beateson (English anthropologist, 1904-1980) in Bruyninckx & Mortelmans (1999) describes the view of including the social relations between people in the context of health (such as the relationship between doctor and patient). Thirdly, the *existential anthroposophical paradigm* can be framed in the context of symbolic interactionism. With this view, the experiences of people are central, which means that personal values, emotions, personal history, among other personal aspects, are as important as the medical circumstances. And finally, the fourth paradigm, the *cultural paradigm*, where most of the values are shared with the *existential anthroposophical* paradigm. However, in this paradigm, there is even more attention given to the definition of health and disease as seen from a cultural and social point of view (Bruyninckx & Mortelmans, 1999). This fourth paradigm, therefore, contradicts the biomedical and system paradigm, as these both share the values of the positivistic approach.

In the approach of Bruyninckx & Mortelmans (1999), the four paradigms of health science according to Lafaille (1993) were used as shown in Figure 2.1 below.

	Natural sciences	*Human Sciences*
Person as an individual	**Biomedical paradigm**	**Existential Anthroposophical paradigm**
Person as part of the society	**System paradigm**	**Cultural paradigm**

Figure 2.1: The four paradigms in Health Sciences according to Bruyninckx & Mortelmans (1999: p 27)

2.2.2 Definition of Quality of Life according to the World Health Organisation

The World Health Organisation (WHO), a specialised agency of the United Nations, has set itself the goal of improving the health of the world population (www.who.int). In 1997, the WHO argued that health and the effects of healthcare are not only an indication of changes in the frequency and severity of diseases, but are also an indication of the improvement of the 'quality of life' (QoL) related to healthcare. It is therefore the case that the WHO has developed two cross-cultural instruments: the WHO Quality of Life - 100 (WHOQoL – 100); and the WHO Quality of Life - BREF (WHOQoL - BREF), which is an abbreviated version of the WHOQoL – 100. Both instruments show a high validity and reliability (Kalfoss et al., 2008). One of the values on which both questionnaires (WHOQoL – 100; WHOQoL – BREF) are based is a definition of 'quality of life', which is explained as:

> *Quality of Life is the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. The Quality of Life is a broad ranging concept affected in a complex way by the person's physical health, psychological*

> *state, the level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.*
>
> (World Health Organisation[8], 1997: p 1).

The definition according to the WHO is closely related to six ‘life domains’, which is what makes it versatile. The life domains are as follows:

1. Physical health
2. Psychological health
3. Level of Independence
4. Social relationships
5. Environment
6. Spirituality/Religion/Personal Beliefs

In the Mental Health Programme of the WHO (1997), the organisation strongly suggests the application of their QoL measurement in order to evaluate the following domains (WHO, 1997):

- Improving the doctor-patient relationship
- Assessing the effectiveness and relative merits of different treatments
- Evaluate the health services
- Performing research
- Policy making

2.2.3 Friction between models

In this study, I have chosen to adopt a holistic QoL model as developed by Bruyninckx & Mortelmans (1999). They combine the four paradigms as previously described, and their model made it possible to use it effectively for the individual needs. Subsequently, Bruyninckx &

---

[8] (http://www.who.int/mental_health/media/68.pdf).

Mortelmans (1999) argued that in current healthcare, quality of life means more than the absence of illness. Furthermore, they proposed that medical clinicians should not hold on to the medical view (biomedical perspective) of a health issue only (Bruyninckx & Mortelmans, 1999). The biomedical view clashes with the status of a chronic disease, in that, the disease will not simply disappear over time, and will persist in the patient for a longer period of time. The work of Bruyninckx & Mortelmans (1999) proposes that personal experiences of illness, especially in those with a chronic condition, are highly relevant, and that by using a holistic approach, which refers to the QoL, the possibility is created to explore, and thus improve, the QoL for the individual. Furthermore, the model creates the possibility of connecting care or a therapeutic alliance where needed.

Nevertheless, using certain holistic perspective may cause limitations. One of the challenges of the model is setting (psychiatric) diagnoses into the context of current society. For instance, psychiatric diagnoses claim a central position in the medical tradition. Even nowadays, daily practice in psychiatry is based on these principles (van Furth, 2014). Moreover, physical and psychological complaints arise in different social contexts, such as in the family, at school/work and in other contacts. Indeed, certain complaints can develop into more severe disorders, such as eating disorders (van Furth, 2014). In order to understand the friction between the view according of the biomedical model and other social models, it is necessary to clarify an important economic choice. In the Netherlands, in 2012, 1.4% of the Gross National Product (GNP) was spent on mental healthcare. By comparison, the economic cost of the mental healthcare in the UK in 2013 was 4.2% of the GNP (mentalhealthorg.uk), and 20% of this amount was attributed to health and social care costs. Overall, the total cost of mental illnesses in European Union countries is estimated at between 3 and 4% of the GNP (GGZNederland.nl). In the Netherlands, politicians made a crucial choice in the treatment of children and adolescents up to 18 years old who had psychological complaints. In January 2015, policymakers started the Act on the Healthcare of Youth. This Act makes no distinction between educational and developmental problems and other severe mental disorders. According to this stance, it is possible that the treatment of a psychiatric Illness may be postponed or may receive an inadequate treatment, as a result of pre-set fees. Thus, regarding this context, it is possible that a person, who develops a severe psychiatric disorder, such as an eating disorder, does not receive the best-adjusted treatment, referring the perspectives according the view of the current leading holistic model.

2.2.4 The quality of life in the perspective of human sciences related to health and illness

Regarding the combination of severe biomedical suffering and the psychosocial issues of people with SE-AN and their struggle in daily life, this section attempts to frame the concept of the quality of life, as seen through the perspective of both biomedical and psychosocial issues. Therefore, I specifically sought literature that was closely related to the terms as described above. The work of Theofilou (2013) attempts to define the concept of QoL and gives insight into the existing means of measuring QoL. According to Theofilou (2013), the measurement of the quality of life can play an important role in the evaluation of treatment. Theofilou (2013) argues that, in her literature search, the term ‘quality of life’ often refers to ‘well-being’. In Theofilou’s (2013) work, she refers to De Leo et al. (1998). According to De Leo et al. (1998, in Theofilou, 2013), the terms are often confused. Sometimes the terms ‘quality of life’ and ‘well-being’ are used to define the other. This fact arose over the years, as a product of many conceptualisations regarding the notion of QoL. Subsequently in her work, Theofilou (2013) poses a broad scope of ‘generic’ and ‘disease-specific’ quality of life instruments and takes account of the subjective perception values, which may be characteristic of mental illness. Theofilou uses the definition as described below:

> *The concept of quality of life broadly encompasses how an individual measures the ‘goodness’ of multiple aspects of their life. These evaluations include one’s emotional reactions to life occurrences, disposition, sense of life fulfilment and satisfaction, and satisfaction with work and personal relationships.*
> (Diener et al., 1999 in Theofilou, 2013: p 151).

2.2.5 Quality of life as seen from a feministic perspective

In this study, I focus on females only[9]. It is the case, therefore, that I will use the context of a feministic perspective in the search for the 'quality of life'. This perception has led me to a broader search in the theses of the University of Humanistic Studies (repository.uvh.nl). Klaverwijden (2010) discusses three feministic movements as seen in the Netherlands, which I elaborate on in the following sections below. This concerns the following movements:

1. The political feminism tendency;
2. The cultural critical feminism tendency and;
3. The postmodern feminism tendency.

The first *'(political) feministic movement'* took place in the last part of the 19th century. Suffrage for women and legal equality were the controversies. Then during the 1970s, as Klaverwijden (2010) describes, a paternalistic healthcare system existed, which led to a particular point of view, that the health care problems of women were reduced to (single) medical problems, treated by pharmacotherapy only, or, that women were attributed with individual psychological factors. Unnecessary individual problematizing took place, and attention to the social conditions and influences of the social environment on the individual were missing.

During the *'cultural critical feministic movement'*, the moral and psychological inequality between men and women were discussed (Klaverwijden, 2010). The cultural critical approach claims a re-evaluation of 'the Female' in order to strengthen the position of women by means of a more positive approach. This approach was based on the insights of the subordination of the *feminine* in the development theories, as seen from a dichotomous perspective, such as, men versus women, hetero- versus homo-sexual, young versus old (van Mens-Verhulst, 2007:1).

---

[9] Section 2.1.2: The prevalence and incidence of Anorexia Nervosa.

The final movement, the *'postmodern feminism tendency'* is based on the principles of the differences between women, with the article by Klaverwijden (2010), for example, referring to the feminine studies performed by Wekker & Lutz (2001) and Wekker (2002). Wekker (2002) described a critical stance regarding the mainly black and lesbian women against the white, heterogenic characteristics of the former feministic approaches. With this, Wekker (2002) concluded that the disregard of the differences between all women could lead to more marginalisation of sub-groups in women, for instance, black, migrant and refugee women. This approach has led to a broad, 'interplex[10] concept and contains a certain amount of scepticism against the principles of equality and difference. This led to a new formulated stance: the postmodern feminist focus on diversity.

2.3 Nederlandse Academie Eetstoornissen (NAE)

In the following paragraphs, I attempt to explain the current Dutch healthcare and scientific situation in the treatment of eating disorders in general. Mainly, the Dutch eating disorder services are closely associated with the Nederlandse Academie Eetstoornissen[11] (NAE). The task of the NAE is to promote scientific knowledge within the connected services. With this aim, the NAE seeks to improve the scientific standard in the eating disorder services, with the aim of delivering high quality care across the country, by the promotion of research and innovative treatment. Furthermore, the NAE takes advantage of the use of the Dutch Guidelines in the Treatment of Eating Disorders (2017). These guidelines are based on the Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders (CPG) (Hay et al., 2014). By these means, the interventions and findings of the Royal Guidelines are thoroughly researched by a broad multi-disciplinary task force, managed by Professor Hoek, in order to adapt the guidelines for the Dutch situation.

---

[10] Interplex: A perspective on diversity: a multidimensional, continuous, dynamic, constructivist approach of how relatively unchangeable differences such as sex/gender, ethnicity, age, sexual preference, class and vision on life are crossing each other, within persons and collectives. (Van Mens-Verhulst, 2003: 34).

[11] (Nederlandse Academie Eetstoornissen) Dutch Academy for Eating Disorders.

2.3.1 Treatment capacity of eating disorders in the Netherlands

The Netherlands has approximately 17,100,000 inhabitants (2018, CBS.nl). Although, the overall rates for the prevalence of eating disorders has remained stable over the past decades in the Netherlands, there is an increase in the incidence of eating disorders in females in the age group 15 to 19 (Smink et al., 2012). Smink et al.'s (2012) research, based on a two-stage study of community samples, measured the estimated incidence and a one-year prevalence rate for Anorexia, and indicated the following rate: 370 per 100,000 young women. In numerical terms, this equates to approximately 6,290 Anorexia patients in any one year. Translated to the GP's practice, this means that there is an average of 1 Anorexia patient per general practitioner.

At the time of writing, the prevalence of SE-AN is 25% of the 6,290 figure, which equates to 1,572 patients (richtlijneetstoornissen.nl). Despite the fact that the current media is giving more attention to the phenomenon of eating disorders, for example, the slightly recent documentary (November 2016) of a young woman named Emma (www.npo.nl), therapists still do not acknowledge a significant increase in patients with EDs.

In order to clarify the question involving the capacity of ED treatment in the Netherlands, I have undertaken some brief research on the internet. Therefore, I visited the individual websites of the specialist services for eating disorders units (SEDU) in the Netherlands and the NAE website (NAE.nl, 2017). In the Netherlands, there are twelve SEDUs. Most of these centres are situated in the urbanised regions in the west of the country. Although there is a link between the appearance of psychiatric illnesses and the degree of urbanisation, Anorexia showed no association with this phenomenon (van Son et al., 2006). Overall, the Dutch SEDUs have an average in-patient capacity of 15 to 20 places (NAE.nl, 2017). However, it is not known what the outpatient treatment capacity is, though, as seen on the NAE website's map, the presence of private therapists, specialising in the treatment of eating disorders is substantial.

2.3.2 Dutch Specialist Eating Disorder Service Units (SEDU)

In the Netherlands, SEDUs are mainly associated with the general mental healthcare institutions. Two (of ten) SEDUs are situated in a general university hospital, however, one of these SEDUs specialises in the treatment of child and youth eating disorders (Erasmus Medical Centre, Rotterdam). The other SEDU is located in the south of the Netherlands and specialises in the treatment of acute Anorexia Nervosa only (Maastricht University Medical Centre). Overall, an exact number of in-patient treatment places cannot be given, along with the fact that, most clinical treatments are reserved for patients with a specifically shorter duration of the illness (< 7 years) (Touyz et al., 2013; NAE.nl, 2017), and they offer an appropriate treatment adjusted for curative treatment (NAE.nl, 2017).

Although there is no evidence-based treatment for AN, there is consensus by most therapists in using a cognitive behaviour treatment method, such as the Cognitive Behaviour Therapy – Enhanced (CBT-E) (Fairburn, 2008; NAE.nl, 2017). CBT-E is designed for the treatment of the most common eating disorders and consists of a ‘trans-diagnostic’ approach. With this method, Fairburn (2008) argues that similarities in EDs occur, and can be approached by using one rationale, based on the over-evaluation of the body and weight (Fairburn, 2008:19). Furthermore, CBT approach is the only evidence-based treatment for Bulimia Nervosa (Touyz et al., 2013; Fairburn, 2008; Le et al., 2017; Agras et al., 2017). Nevertheless, in the case of Bulimia Nervosa, clinicians also use a family-based therapy approach, often based on the principles of ‘the Maudsley Approach’ (Le Grange & Lock, 2009 in Maudsleyparents.org, 2017). The Maudsley Approach is used with both child and youth in- and out-patients. The Maudsley model (i.e. Grange & Lock, 2009) is designed for the treatment of children and young adolescents with eating disorders and focuses on the role model of parents.

2.4 Treatment of Severe and Enduring Anorexia Nervosa within the SEDU

In the Netherlands, current treatment programmes for eating disorders mainly focus on the physical and psychological recovery of patients with *acute* Anorexia Nervosa, and more positive results have been reported in younger patients with a shorter duration of the illness (Agras et al., 2014; Lock, 2015). However, treatment interventions focussing on those with shorter illness trajectories may not be appropriate for those with SE-AN (Touyz et al., 2013), since short-term treatment seems to have a minimal effect on persistent ruminations pertaining to weight, food, and body shape (Touyz et al., 2013). It is precisely these beliefs that are inextricably linked to SE-AN. In conversations, healthcare professionals identify the need for non-specific medical palliative care for patients with SE-AN (Strober, 2010; Touyz et al., 2013). It seems reasonable, therefore, to suggest that the complexity of the condition as a severe and chronic disorder requires a different treatment paradigm (Tierney & Fox, 2009; Touyz et al., 2013; Touyz & Hay, 2015). According to Strober (2010), Williams (2010) and Touyz, (2013), full recovery from every manifestation of SE-AN should not be the primary goal of treatment for individuals with the condition. The focus should be on improving the quality of life and avoiding failure experiences in treatment that further discourage patients (Touyz & Hay, 2015).

In the Netherlands, approximately 1,600 people suffer from SE-AN. Although SEDUs mainly focus on the more acute forms of eating disorders, some of the units offer treatment to SE-AN patients. Three SEDUs offer a minimum of a 2-hour per week group treatment in cooperation with, or led by, experienced patient-experts (Rivierduinen.nl; Amarum.nl; Altrecht.nl). Two SEDUs offer in-patient treatment for SE-AN patients, based on the principles of Specialist Supportive Clinical Management (SSCM) (McIntosh et al., 2006, 2010) (Emergis.nl; Altrecht.nl). The SSCM (McIntosh et al., 2006, 2010) intervention aims to help individuals improve their QoL and to increase their motivation, which enables them to make progress on their recovery from core AN pathology (Touyz et al., 2013). SSCM uses clinical management such as education, care and support and supportive psychotherapy. The therapeutic relationship focuses on increasing confidence in treatment. Supportive psychotherapy supports the patient by providing advice and rewarding him/her. However, there are no exact figures as to the number of patients who can benefit from these programmes.

2.5 The SEDU as seen from a personal perspective

I work full-time within the SEDU as a master nurse specialist (MANP) combining healthcare programme management tasks, in a mental health institution situated in the southwest of the Netherlands (Emergis.nl). This SEDU offers in- and out-patient treatment to ED patients from the age of 15 onwards, who are domiciled in the Netherlands. Thus, ED patients all over the country can sign up for the service. The SEDU organises treatment for approximately 300 people per year (based on the figures for 2014, 2015, 2016 and 2017) (private data).

Within the SEDU, there are two main models. The first model, based on the theoretical background of Cognitive Behaviour Therapy – Enhanced (CBT-E) (Fairburn, 2008), emphasises full recovery. CBT-E aims at a treatment for ED patients demonstrating an acute form of the illness or patients who are highly motivated to overcome their eating disorder. The CBT-E (Fairburn, 2008) is, therefore, a formal treatment, based on a trans-diagnostic model, which means that the protocol focuses on the various types of eating disorder and makes no difference between sub-types, such as AN, Bulimia Nervosa and binge eating disorder (BED). Furthermore, CBT-E (Fairburn, 2008) focuses on mostly behavioural and cognitive disturbances, which are provoked by and related to the eating disorder.

The second model affects the principles for rehabilitation and the increase of the quality of life (QoL) in living with an ED. Therefore, the Specialist Supportive Clinical Management (SSCM) (McIntosh et al., 2006, 2010) is used. According to McIntosh et al. (2006) and Touyz (2013), SSCM aims to help individuals improve their QoL and to increase their motivation for further therapeutic alliance. In addition, it enables them to make progress on their recovery from core Anorexia Nervosa pathology. To achieve this, SSCM uses clinical management, such as education, care, support and supportive psychotherapy. The therapeutic relationship focuses on the increase of confidence in the treatment. Supportive psychotherapy aims at providing advice and the positive rewarding of patients. In the treatment of people with SE-AN, the SEDU adopted the SSCM model, (McIntosh et al., 2006, 2010) regarding a significant part of the adherence of people with SE-AN involving a request for improving their QoL in living with an eating disorder.

Working with the patient, a multi-disciplinary team offers a treatment specifically tailored to the health problems that the patients experience. Furthermore, in the Dutch situation, it is important to note that each patient has a personal healthcare manager, appointed to deal with the specific needs of the patient and they are aware of and responsible for all the healthcare processes of the patient (ggzkwaliteitsstatuut.nl/). Within this particular SEDU, it is policy that this role can only be carried out by a BIG[12] registered healthcare professional (Bigregister.nl), which means that a psychologist, a psychiatrist or a nurse specialist (also, nurse practitioner) might fulfil this task.

Over the years, I have noticed an increase in the number of SE-AN patients, with previously, relatively young people signing up for such treatment. Nowadays, however, the SEDU more frequently sees requests for SE-AN treatment, and often, these requests are from women aged 23 and older, who have developed SE-AN and suffer from serious medical and psychological complaints (see Section 2.1.5: Severe and Enduring Anorexia Nervosa). These people have a legitimate request for help and, sometimes they wish to stay in their own environment, or at least, spend as short a time as possible making use of the in-patient service. Although the SEDU is well equipped to deliver appropriate care to people with serious somatically comorbid suffering, it occasionally happens that, after the screening and intake process, or even after a short treatment period, people sometimes decide they no longer wish to receive the curative

---

[12] BIG: Beroepen op de Individuele Gezondheidszorg (Occupations in the Individual Healthcare), registered by law.

treatment, often as a result of both medical complications and the duration of the illness, combined with former failure treatment experiences. I personally experienced a number of cases which were the result of a failure in our current healthcare system. It appears that there is no appropriate treatment in place for this patient group. With this noted, I recognise the views of Strober (2010) and Touyz et al. (2013), who, in their studies, strongly argue for the following stance: That patients with SE-AN should be in contact with healthcare professionals, and that the need for non-specific medical palliative care is identified (Strober, 2010; Touyz et al., 2013). Furthermore, they advocate for a different treatment paradigm (Tierney & Fox, 2009; Touyz et al., 2013; Touyz & Hay, 2015). According to Strober (2010), Williams (2010) and Touyz (2013), full recovery from every manifestation of SE-AN should not be the primary goal of treatment for individuals with the condition. The focus should be on improving the QoL and avoiding failure experiences in treatments that further discourage patients (Touyz & Hay, 2015).

As seen from my perspective, an appropriate professional treatment should be offered, with respect for the individual, and the help offered to the patient should be according to their requested, and which should be viewed from their perspective. For example, even if the patient formulates a palliative question, such as, ‘Help me learn to live with this condition’, this should be addressed. However, the current ‘healthcare landscape’ does not, as yet, provide these individuals with answers to these requests for help. Nowadays, I attempt to find some solutions by enabling and co-operating with the flexible assertive community treatment teams (F-ACTs) of the Dutch mental health institutions (f-actnederland.nl). The F-ACT method (f-actnederland.nl) is designed to offer treatment to people with core severe and enduring psychiatric symptoms, and is based on six principles, which are:

- We are there where the client wants to succeed.
- We support the social networks of the client.

- We find and bind the transmural chain of care[13].
- We treat according to the multi-disciplinary guidelines.
- We support rehabilitation and recovery.

Bearing in mind the assumptions above, SE-AN patients can benefit from appropriate support in their own environment regarding the adjustment of FACT. However, in the field of work, such co-operation is challenging. In the Netherlands, most of the FACT healthcare workers are not trained to accompany SE-AN patients, as these patients are mostly excluded from FACT regarding their exotic appearance caused by their significant underweight. This has led to a lack of specialist knowledge of eating disorders in general psychiatric care, specifically knowledge of severe physical comorbidity in eating disorders is lacking, yet this is a necessary requirement in the support of those with SE-AN. A further problem to overcome is the distance a patient is from the SEDU. SEDUs offer treatment to every Dutch inhabitant with an eating disorder. Often, after in-patient treatment, a follow-up contact in the patient's own region is proposed, preferably with a trained eating disorder professional. However, for people who live at a distance from an SEDU, this follow-up is not always possible, if the issue of the distance cannot be resolved. In conclusion, little or no help is available for this group (Hoek, 1995, in Goss & Allan, 2009).

2.6 In search of a research question

In the previous sections, I have defined several important concepts which are used in this research, such as, Anorexia Nervosa; the severe and enduring form of the disorder; quality of life; and the current treatment of eating disorders in the Netherlands. These insights demonstrate the importance of the research question. In this section, I present the research question, as well as the aim and objectives of the study.

---

[13] Cooperation of care, in-and out-patient and community forms of treatment cooperating with each other (https://www.medicalgroep.nl/transmurale-zorg/)

In order to support and frame this study, the research question is formulated as: *Which factors are responsible for a reduced quality of life in people living with a diagnosis of severe and enduring Anorexia Nervosa?*

In the following section, I present the aim and objectives of this project.

2.6.1 Aim and objectives

The aim of this study is to generate an in-depth understanding of the phenomenon regarding the ‘the experiences of life’ of people as influenced by the symptoms of severe and enduring Anorexia Nervosa.

With regards to the objectives of this study, these are as follows:

- to provide fresh insights of the life experiences of people with severe and enduring Anorexia Nervosa;
- with the fresh insights gained, this will enable therapists to contribute to the empowerment of the SE-AN patient, in order to provide a deeper understanding of the illness;
- with a deeper understanding of the condition, this will allow, not only the empowerment of the SE-AN patient, but will also empower their relatives and friends, and will improve the social integration of the person with SE-AN;
- with the above, an improvement in the quality of life for the person with SE-AN will be achieved.

The findings of the study will be described in Chapters 7, 8, 9 and 10, and these will be discussed and compared with extant literature in Chapter 11. Chapter 12 will elaborate on a theory of the quality of life of people living with a diagnosis of severe and enduring Anorexia Nervosa. The findings may then contribute to the current healthcare in the treatment of people with severe and enduring Anorexia Nervosa.

2.7 Summary

In this second chapter, I have elaborated on the prevalence and incidence rates of Anorexia Nervosa and the severe and enduring form of the disorder. I have presented different definitions of Anorexia Nervosa, tailored in order to reach the reader for whom the definition was created. Furthermore, a summary of the diagnosis of Anorexia Nervosa according to the DSM-5 is given. I have presented definitions of the QoL, as seen from a historical perspective, and how the concept of the QoL was introduced into the field of medicine and how, over time, this definition has been adjusted. I have then framed the concept of QoL in a feministic approach, and described the principles of the Dutch healthcare system for the specialist treatment of eating disorders. In this regard, I have, therefore, explained the concepts of NAE, SEDU, and the treatment of SE-AN on the SEDU. Furthermore, I have illuminated the concept of severe and enduring Anorexia Nervosa as described in the existing literature, as well as the current landscape of eating disorder treatment in the Netherlands, and also the treatment of SE-AN within the SEDU, as seen specifically from my own perspective as a nurse practitioner. Finally, I elaborated on the research question, the aim of the study and its objectives.

Chapter 3 Methodology

3.1 Introduction

In this chapter, I present the methodology for this project, adopting a qualitative constructivist Grounded Theory approach (GT), as described by Charmaz (2006). Hence, I explain the development of the methodology and specifically discuss the execution and positioning of the Literature Review, as well as the ontology, the epistemology and the theoretical perspective. The study is underpinned with the philosophical insights of Constructivism, although, a debate regarding the scientific stances of Positivism, Post-Positivism and Critical Paradigm are also elaborated upon, as Constructivism reveals the decision-making processes from the start of the study. Next, I define ‘Feminism’, and I elaborate on the importance of the feministic features that refer to this project, and thus, to my choice of the use of the feministic insights of the data presented. Finally, I explain the development of the GT method, according to Charmaz (2006) and expand on the logical steps which explain the constructivist methods after Charmaz in the subsequent chapter (Chapter 4).

3.2 Introduction of the Literature Review

I have given special attention to the scheduling of carrying out the Literature Review within the process of the study, as there is a continual discussion as to *when* to conduct this component of research. Hence, I will comment on my decision by explaining the literature findings in Chapter 11, the discussion chapter. In the constructivist approach, extant literature findings function to underpin the placing, defending or rejecting empirical findings, which are revealed from the leading constructs of the women with SE-AN. Moreover, adding literature findings in the findings chapters is not problematical, as long as the data is *grounded* (Charmaz, 2006).

3.2.1 When to conduct a literature review?

In classic GT, one of the fundamental methodological steps is the execution of a literature review. In GT, the carrying out of the literature review before the data collection and analysis is often discouraged. GT scholars consider this as reasonable, since the prevailing opinion refers to the following insight that the literature review is meant to strengthen, position and discuss the findings within the study rather than guiding the project at the start (Glaser & Strauss, 1967; Glaser, 1992; Strauss & Corbin, 1990; Ramalho et al., 2015). Classic GT (Glaser & Strauss, 1967) is strongly opposed to the influences of existing empirical knowledge (of the topic of research). With this method, the researcher develops a theory, rather than testing an existing one, and thus, is able to look at the data with 'fresh eyes' (Ramalho et al., 2015; Glaser & Strauss, 1967; Strauss & Corbin 1990; Charmaz, 2006). Subsequently, slight differences of opinion arose between the founding fathers of classic GT. Glaser (1992) argued that the reading of literature directly related to the field of inquiry should be avoided, since this can significantly influence the ideas and perceptions of the researcher. Strauss & Corbin (1990) were, however, less rigid on this topic. They argued that reading empirical, or non-empirical, literature on the topic does not adversely affect the construction of the theory directly, as long as the researcher is aware of the influences and maintains an attitude of scepticism (Strauss & Corbin, 1990; Ramalho et al., 2015). The current project follows the methodology developed by Charmaz (2006), whereby her perspective suggests the value in delaying the literature review, although she advocates not being too rigid on this. Regarding the view of Social Constructivism, which Charmaz (2006) proposes, this suggests the researcher's perspectives, knowledge and background are somewhat important. She states that "*We are a part of the world we study and the data we collect*" (Charmaz, 2006: p 10).

In terms of my personal situation, as a Clinical Specialist Nurse in Eating Disorders, I am not without some empirical knowledge of the topic of research (see Chapter 1 and Chapter 2 (Section 2.5 - The SEDU as seen from a personal perspective). However, according to Ramalho et al. (2015), the method of delaying the literature review might concern some researchers, for example, with regards to getting permission from stakeholders to perform the research. Alternatively, in terms of obtaining financial support for carrying out the empirical research, as universities, ethics committees and funding organisations often require a brief but clear review of the topic of interest. Such motivations make it reasonable to perform a literature review before the data processing. Although conducting a literature review at the start of a project is a logical and fundamental step in the method, I have chosen to follow Charmaz's (2006) classical approach.

As in classic GT, delaying the literature review, is basically for two reasons. Firstly, before and during the process of the study, I have a particular perspective based on the empirical findings of previous research, which existed during my career as a nurse at the eating disorders service (see Chapter 1). While writing this, I realised that I have a significant insight into the study topic and I cannot simply disregard this insight during the current study, because I am acting here as a researcher, rather than as a clinician. With awareness of this principle, it forced me to use empirical material, based on findings related to this project. Secondly, during the interviews with the women, it may well be the case that new issues will be raised, which I was not aware of at the beginning of the study. According to this perspective, I would not have carried out a search for these topics, especially at the start of the study, since they may not have been considered pivotal at that stage. Thus, to avoid performing the literature study twice, it may be better to delay this. In the discussion chapter (Chapter 11), and in the findings chapters, as long as the findings are sufficiently grounded, the insertion of the extant literature findings is considered as additional data during the data analysis, the literature findings will be discussed at this point (Charmaz, 2006). In this way, I will elaborate on my findings of the extant literature to compare, defend and position new theoretical insights *after* the data processing (Charmaz, 2006). Finally, in the attempt of making my thinking strategies transparent, the literature approach will be elaborated on in Section 6.8 - The literature review method.

3.3 Qualitative or quantitative approach, what fits best?

In this paragraph, I propose a qualitative research design, although the research question might have directed me to a quantitative approach, since there are many topics of interest and existing (quantitative) questionnaires to measure the QoL. Hence, I define my choice for a qualitative research approach, underpinned by the compliant theoretical-philosophical frames [14] . The use of up-to-date, well-validated outcomes of scientific research is indispensable, in order to provide an appropriate range of therapy and various interventions for care (Hofman et al., 2006: pp 13-15). Nowadays, therapists, clinicians, patients, insurance companies and other parties, such as policy makers, are interested in actual scientific data and each of them is concerned with its own interests in the data knowledge. For example, a clinician and a patient are both interested in the type of therapy that fits best; insurance companies want to know the costs of the care; and, policymakers are more likely to be interested in a combination of aspects of healthcare. Furthermore, in the training of health professionals, a significant part of the training is reserved for the understanding and interpreting of the scientific research (Hofman et al., 2006: pp 13-15; Rothman, 2002: Chapter 1).

According to a positivist stance, modern medicine has its roots in clinical epidemiology which claims a major contribution into the most basic rules around medical and health work (Rothman, 2002). Clinical epidemiology is the study of the distribution and determinants of disease frequency (Rothman, 2002: p 1). In support of different opinions, I decided to search for suitable definitions, in terms of evidence-based medicine. An appropriate definition is given below:

> *Clinical epidemiology applies specifically on the study of quantitative aspects of the course of illnesses. Therefore the four categories according to Hippocrates[15] are used: etiology, diagnosis, prognosis and therapy. Clinical epidemiology studies the outcomes of illnesses (cure, complication, death) in the function of the factors that influences the outcomes.*
>
> (Hofman, 2006: p 13).

---

[14] See Sections 3.4.2 - Constructivism and Section 3.4.3 - Feministic paradigm.

[15] Hippocrates of Kos, Born 460 BC, Greek doctor, founding father of modern medicine.

Clinical epidemiology is related to a positivistic ontology, which posits strongly for a deductive research style, and concentrates on the execution of a quantitative research method. Nevertheless, it is, therefore, vital to elaborate on the relationship between evidence-based medicine and clinical epidemiology. Firstly, however, I will define the concepts of evidence-based medicine and clinical epidemiology, which are given below:

> *Evidence–based medicine is way of thinking which assumes that medical treatment is, as much as possible, based on facts that are obtained from scientific research.*
>
> (Offringa et al., 2008: p 30).

A further suitable definition, referring to evidence–based medicine, is also given below:

> *Evidence-based medicine is the meticulous, explicit and judicious use of current best evidence to make decisions for the individual patient. The practice of evidence-based medicine means integrating the individual clinical expertise with the best external evidence obtained from systematic research. The preferences, wishes, expectations of the patient play a central role in the process of decision-making.*
>
> (Offringa et al., 2008: p 22).

In illustration of epidemiology connected to the topic of the current study, the WHOQoL-100 and the WHOQoL-BREF (World Health Organisation - Quality of Life measurement scales) are examples of measurement instruments designed to measure QoL. The QoL can be interpreted as an outcome of clinical epidemiology (see also Section 2.2.2 - Definition of Quality of Life according to the World Health Organisation). A brief literature search in different databases (PubMed, Medline, EBSCO and Google Scholar) shows an overwhelming variety of QoL measurement instruments. Some QoL instruments are designed to measure QoL in general, for example the Short Form-12 Health Status Questionnaire (SF-12 in Ware et al., 1998), is indicated as a well-validated instrument and measures various dimensions of health, including the limitations due to physical and mental illness. Similarly, the Flanagan Quality of Life Scale (QOLS) (2003) is a reliable and validated 16-item measurement scale, designed to measure the QoL in people with chronic suffering (Burckhardt & Anderson, 2003). The QOLS claims to measure the QoL in people suffering with the long-term effect of psycho-trauma.

Other instruments which focus on the QoL are connected to a disease (of any kind). However, by using ‘illness-specific questionnaires’, comparing outcomes is rarely possible. Thus, most professional users prefer using two instruments, one general instrument and one illness-specific instrument (Busschbach, 1997).

Consequently, the brief literature search conducted prior to the commencement of the study brought me to the next specific instrument: *The Eating Disorder Quality of Life Instrument* (EDQOL) (Engel et al., 2006). The EDQOL is a 25-item questionnaire. It assesses the quality of life in people suffering from eating disorders, and it contains four subscales: (1) psychological; (2) physical and cognitive; (3) financial; and (4) work or school. The EDQOL is specifically designed to assess the different aspects of the quality of life of people with Anorexia Nervosa. The EDQOL was used in a randomised controlled trail conducted with participants who suffer from SE-AN (Touyz et al., 2013). In Touyz et al.’s article, the authors argued that the instrument is a standardised and well-validated instrument.

In summary, although a scale of instruments have been developed to measure QoL, and the instruments are validated and thus show reliability, the measurement instruments focus on the QoL in combination with, or without a treatment for certain diseases (Busschbach, 1997).

However, a study of the QoL does not have to be aligned to quantitative research only (Busschbach, 1994 [Addendum 2]: p 14). A qualitative design makes it possible to search for the more subtle effects of a treatment, such as, the experience of the illness and/or the interventions patients have had, as well as the facility to examine the burden placed upon spouses, family and partners. Busschbach (1994) argues that qualitative research is a more sensitive method to collect changes in the condition of people. With a qualitative approach, not only the positive effects of an intervention, such as the treatment or the ‘state of being’, can be monitored, but also the negative effects of both phenomena can be understood.

In conclusion, whilst focusing on several measurement scales for QoL, none of the existing quantitative measurements examine the QoL of people with SE-AN, and neither do the measurements examine their subjective experiences regarding their treatment; their experiences in their current situation; and/or the experiences of SE-AN from the point of view their family, partners and societal environment.

With this statement, I do not proclaim that SE-AN patients do not suffer from a serious disease if it is not measured. Indeed, the impact of SE-AN is significant, as it disrupts life, and thus, the quality of life. SE-AN can be seen as a subjective perception of the person it affects only, and it is constantly influenced by social and environmental changes. Consequently, I have chosen to conduct a qualitative approach with regards to the subjective perception, regarding the value of a qualitative approach, as it will provide additional insights regarding this project.

3.4 Development of the Methodology

It is important to frame the research process, the method of approach and how this will enable me to answer the research question. Therefore, I have used the principles of social research as described by Crotty (1998, reprint 2015). Here, I explain the development of the methodology, and justify the choice of the methods I adopted. These methods are the technique of data collection and the analysis specifically connected to the constructivist approach of Charmaz (2006) (Crotty, 1998: p 3). Furthermore, the insights of Crotty (1998) are used to refer to the logic of the methodology, rooted in the theoretical perspective, and therefore, I use a feministic approach, and in the epistemology, I use Constructivism. In the view of Crotty (1998), he considers the methodology as one of the four basics fundamental to research (Crotty, 1998: p 2). These four basics are:

- what methods will be used;
- what methodology justifies the choice and use of methods;
- what theoretical perspective is the methodology build on; and
- what epistemology lies behind the theoretical perspective

(Crotty, 1998: p 2)

Crotty (1998) then argues that these four basic elements inform each other and cannot be separated. In order to define these concepts, Crotty elaborated on his framework, (Figure 3.1) demonstrating a scaffolding of the four elements (Crotty, 1998: p 4).

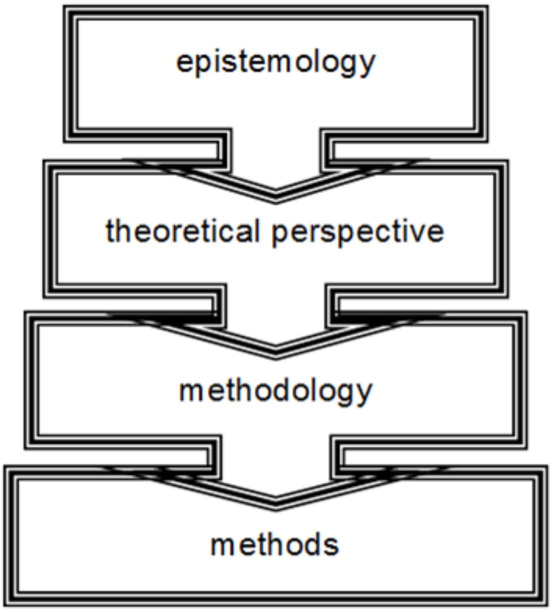


Figure 3.1: Scaffolding of the four elements (Crotty, 1998: p 4).

3.4.1 Ontology

Regarding the ontology in this study, firstly, it is important to define this concept. Ontology is described by Crotty (1998: p 10) as *"[t]he study of being"* and is concerned with the perspective of the *"kind of world we are investigating, with the nature of existence,"* and *" with the structure of reality as such"* (Crotty, 2003, in Ahmed, 2008 p 2).

Crotty (1998) has chosen not to place ontology in the scaffolding, as illustrated above (Figure 3.1), and proposes that epistemological and ontological insights co-operate with each other and inform the theoretical perspective. According to Guba & Lincoln (1989, in Ahmed, 2008: p

2), the ontological issue can be discovered in the research question, the *'what is there that can be known'* question, or the *'what is the nature of reality'* question.

In science, Vorst (2009) suggests that two ontological opposites are there to distinguish, the positivistic perspective and the social constructivist perspective. In Positivism, there is only one reality that is independent from the position of the viewer, and this reality functions according to the immutable laws of nature. An epistemological stance, which connects with the ontological positivistic perspective, is Objectivism, as determined by Rand, a Russian-American philosopher (1905-1982). According to Rand (aynrand.org), social reality is not influenced by the interpretations of the individual, but is illustrated by the stance that, *"[f]acts are facts, independent of any consciousness"* (aynrand.org).

In Objectivism, it is assumed that social phenomena cannot be influenced, which means that these phenomena can be studied with a deductive study methodology (see also Section 3.3 Methodology).

Social Constructivism uses a relativistic view on reality that is not dominated by natural laws. Smaling (2010) describes the leave-taking of representationalism in searching for the truth, which involves the idea of representing an external reality in theories, propositions and concepts. Leaving this idea means that the 'truth', conceived as a correspondence between the propositions and the external reality, is invalidated, since scientific knowledge is not a picture as such, but is either a reflection or a representation of the external reality (Smaling, 2010).

Thus, regarding this current project, the ontology is the social world of the meanings, thoughts and interpretations of the SE-AN women patients in the SEDU, as well as my supervisors and myself. In other words, the ontology in this research is the consideration of the social constructs as experienced by the parties involved. In the next section, I elaborate on the epistemology of this study, whereby I use the philosophical stance of Charmaz (2006), which is built on

Constructivism (Vygotsky, 1896-1934; Piaget 1896-1980).

3.4.2 Epistemology

Regarding the four elements as described in Section 3.4 (Figure 3.1) (Crotty, 1998), it is important to understand what these concepts mean. According to Crotty (1998), the concept of epistemology is *"[t]he way of understanding and explaining how we know what we know*" (Crotty, 1998: p 3). The theory of knowledge is embedded in the theoretical perspective and thereby in the methodology (Crotty, 1998: p 3). Constructivism underpins my epistemological stance which is closely related to that of Charmaz (2006). Charmaz uses Constructivism as a philosophical insight within her approach to Grounded Theory. In my research, it is important to understand the perspective of all involved parties (see also Section 3.2.2 - Ontology). Hence, I will systematise the tentative concepts by constructing the '*sensitizing concepts'*, which provoke the pursuit of research ideas and sensitize the researcher to ask particular kinds of questions about the topic of interests' (Charmaz, 2006: p 16). With this process, this constructivist perspective connects to an explorative empirical research design (Vorst, 2009).

3.5 Theoretical framework

In the next section, I expand on the philosophical insights which are used in this study: Grounded Theory, according to Charmaz (2006), and Constructivism. Furthermore, a feministic perspective is used to frame the study. This approach is chosen due to the fact that, in this project, I focus on females only (see Section 2.1.2 - The prevalence and incidence of Anorexia Nervosa and Section 2.2.4 - Quality of life as seen from a feministic perspective). As I am female and because the constructivist stance is a foundation of this project, I want to take account of my own female view on the world as experienced.

3.5.1 Constructivism

To understand Constructivism, it is useful to place this philosophical view in the context of other philosophical insights as used in research (Guba & Lincoln, 2005; Crotty, 1998).

According to Crotty (1998: p 42), Constructivism is a learning theory, which is the opposite of an Objectivism stance. According to Crotty, Objectivism is *“[t]he notion that truth and meaning reside in their objects independently of any consciousness*” (Crotty, 1998: p 42). The objectivist stance was developed in the Ancient Greek philosophy and is still used as an epistemological background in current Western science, such as in a quantitative approach (Baarda, 2014: Chapter 2; de Jong, 2008).

Constructivism, according to Guba and Lincoln (2005, in Denzin & Lincoln, 2005: pp 203-204), can be considered as a more extreme approach, as it denies the truth (causality and the laws of nature), unless the truth is built on construction. Guba and Lincoln (2005) argue that facts are only valuable as seen in a network of values. For instance, in their view, research conclusions cannot be generalised, as they are contextually determined. Guba and Lincoln (2005) place their constructivist paradigm as the opposite of three scientific paradigms: Positivism; Post-positivism; and the Critical Paradigm. These stances are, nevertheless, expanded upon in the following section

Constructivism emerged through philosophical insights in the early twentieth century, and is characterised as the knowledge resulting from the thinking activities of the individual, in real life, to generate meaning. Man connects new knowledge to the knowledge he already has. Piaget, a mental development psychologist (1896-1980) and Vygotsky (philosopher, 1896-1934) are regarded as the inspiration behind Social Constructivism (Smaling, 2010) (see also the illustration of the dialogue below: Figure 3.2 - Papert on Piaget, 1999). Constructivism is a research paradigm that denies the existence of an objective reality, stating that realities are social constructions of the mind, and, that there are as many constructions as there are individuals (Guba & Lincoln, 1989: p 43). Furthermore, Guba & Lincoln (in Denzin & Lincoln, 2005) argue that reality is built on community consensus. This stance generates the following questions: ‘What is ‘useful’?’ and ‘What has ‘meaning’?’. In the view of Guba & Lincoln (in Denzin & Lincoln, 2005: Chapter 8: p 197), the criteria for judging validity and credibility are not absolute, thus causing the fact that meaning-making activities are the central interests of the constructivist researcher. Constructivist scholars argued the following stance that the researcher is a part of the world that is studied, and that likewise, the researcher will construct grounded theories according to their own history and their present interactivities with people, perspectives and practice (Charmaz, 2006: p 10).

Piaget: What makes the wind?
Julia (age 5): The trees.
Piaget: How do you know?
Julia: I saw them waving their arms.
Piaget: How does that make the wind?
Julia: Like this (waving her hand in front of Piaget's face). Only they are bigger. And there are lots of trees.
Piaget: What makes the wind on the ocean?
Julia: It blows there from the land. No, it's the waves

Figure 3.2: Papert on Piaget: Time Magazine's special issue on *The Century's Greatest Minds* (1999: p 105).

3.5.2 Constructivism versus Social Constructivism

It appears that the concepts of Constructivism and Social Constructivism are often confused (Smaling, 2010). Therefore, the term 'Constructionism' is used. Social Constructivism, which is a learning theory as well, emphasizes the importance of social and cultural interactions while gaining knowledge. Gergen (1985, 2001, 2009 in Smaling, 2010) argued that common versions of Constructionism are mainly based on two principles, which are: 1.) An internal cognitive reality rather than the external social reality, or, 2.) The opposite, according to Gergen (in Smaling, 2010), that Social Constructivism is mainly influenced by the social reality.

In Social Constructivism, the thinking process, knowledge, and the behaviour of the individual is the departure point (Smaling, 2010), which is influenced by the historical, cultural, social and political factors of the individual. Furthermore, contextual influences are acknowledged more than the material ones. Vygotsky (1896-1934) is seen as the inspiration of this philosophical movement. Social Constructivism, in the opinion of Vygotsky (Smaling, 2010), is also known as the opposite of the Cognitive Constructivist stance, according to Paiget (1976, in Smaling, 2010). In Cognitive Constructivism, the historic, the cultural and the social factors are less important.

In the *Handbook of Constructionist Research* (Charmaz, 2008), Charmaz stated that Social Constructivism in Grounded Theory encourages innovation, because of the possibility of developing other theoretical interpretations of the studied life. As an important note, Charmaz (2008) refers to her own work (2006), wherein she explicitly stated the Constructivist Grounded Theory as an attempt to differentiate it from the objectivist influences. In her work in 2008, Charmaz does not support the radical Subjectivism as assumed by some constructivist researchers. Furthermore, she proclaims the epistemological roots of Social Constructivism in her former work.

In conclusion, although I have based this project on the Constructivist Grounded Theory approach according to Charmaz, I do follow her later insights (Charmaz, 2008) regarding Social Constructivism. Thus, in this research, I recognise and include findings of the studied life, as influenced by historical, social and cultural factors.

3.5.3 Positivism, Post-Positivism and the Critical Paradigm

Attempting to understand the constructivist stance, it can best be explained by expanding upon the opposite philosophical stances, such as Positivism, Post-Positivism and the Critical Paradigm. According to Bryman & Becker (2012), the philosophical paradigm of Positivism is described as follows: *"Positivism posits that the social reality can and should be studied by using scientific methods only"* (Bryman & Becker, 2012: p 126). In Positivism, meanings, beliefs and social constructs are not empirical, and thus, they do not exist in science (Bryan & Becker, 2012). Guba (1998: p 19) explains the fact that in the context of science, the word 'positive' can be seen in the history of the law and in religion. In science, 'positive' is not the opposite of 'negative', but as Guba suggests "*positive religion and positive law is not the* *outcome of speculation; it is something that is posited, it is a 'given'*" (1998: p 19-20). With his view, Guba (1998) argues that the world, as seen by positivistic researchers, is an abstract of the real world that we are living in. To illustrate this stance, Guba (1998) uses the following metaphor: "*watching a map to search the road, people are looking at a flat piece of paper; however, in the reality, the world is curved and full of obstacles*" (p 28).

Post-Positivism (Popper Scientist and Philosopher, 1902-1994; and Kuhn, Physicist, Historian and Philosopher of Science, 1922-1996), also known as the Empirical-Analytical Approach, arose from Positivism and takes account of the human experience as a building block of the paradigm, better known as Naturalism. However, Post-Positivism excludes interpretations as much as possible, which means that (human) observations must be tested and criticised by systematic evaluation such as, for example, the conduct of evaluation research In Guba's (1998) explanation to the evaluation systematics (p 29), he refers to Heisenberg (1901-1976) and Bohr (1885-1962), who were both physicists. Heisenberg was one of the founders of Quantum Theory, a phenomenon raised out of positive science. However, during his lifetime, the phenomenon could not be tested by existing methods. In his work, Bohr, a Danish physicist, demonstrated the structure of the atom. There were, however, differences of approach between the two scientists. On the one hand, Heisenberg had an epistemological problem, since, in those days, there were limitations in determining subatomic dynamics, whereas Bohr had an ontological problem, in that, at that time, people did not know what subatomic particles were (Guba, 1998: p 30).

Finally, the Critical Paradigm has its roots in Marxism. Marx (1808-1883, German thinker) and Engels (1820-1885, philosopher and social scientist) were the founding fathers of the Marxist political-philosophical stance, which was responsible for several modern social theories and ideas. The Critical Paradigm embraces social involvement, and in addition, Marxism criticizes the social domination of capitalism and, in research, the empirical-analytical angle in dominant scientific methods (http://www.montesquieu-instituut.nl).

3.5.4 Social Constructivism according to Charmaz

The methodology, as well as the methods, in this project are based on the principles of the Grounded Theory of Charmaz (2006). For this reason, I have elaborated on the situation of my work environment with regards to my personal perspectives (see Chapter 1 - Introduction and Section 2.4 - Treatment of severe and enduring anorexia nervosa within the SEDU. Regarding the findings, I then attempt to link any substantial new information to already-existing and useful theoretical frames.

A GT study design, according to the Constructivism methodology of Charmaz (2006) is chosen, since the Constructivism paradigm might help to gain a deeper understanding of the research problem. Moreover, I am, in the role of researcher, as well as a therapist a professional who treats people with SE-AN. Thus, knowledge of both the researcher’s experience and knowledge of the informants will help strengthen the other. Charmaz (2006, 2008) emphasizes examining the relativity of the researcher‘s perspectives, their position, their practices and the research situation itself (Charmaz, 2008: p 398). Charmaz (2006) argues the following:

> *We are a part of the study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices*
>
> (Charmaz, 2006: p 10).

Thus, this method studies the social, emotional and day-to-day processes and has a focus on various levels of analysis of the quality of life and the social issues of people with SE-AN. Furthermore, the method studies the experience processes and interpretations of the women with SE-AN; of myself as a researcher, and as a professional; and also of the senior researchers involved. Finally, in addition, the method also examines additional literature. Together, these processes lead to a constructivist theory.

3.6 Feministic Paradigm

This project uses a constructivist approach according to Charmaz (2006). With this view, the experiences, meanings and knowledge of the researcher is a substantial part of the data interpretation (see the earlier Section 3.4.2 - Constructivism). In addition to the choice of a feministic perspective, I am female and, in this study, I focus solely on females (see also Section 2.1.2 - The prevalence and incidence of Anorexia Nervosa and Section 2.2.4 - The quality of life as seen from a feministic perspective).

3.6.1 A definition

In the search for an appropriate definition of 'feminism', I have performed a broad search on the internet by using Google and Google Scholar search engines. According to the *Oxford Dictionary*, 'feminism' is described as "*The advocacy of women's rights on the ground of the equality of the sexes*" (https://en.oxforddictionaries.com/definition/feminism).

A definition by Lewis, a female humanist minister, was found on *thoughtco.com* (2017). Lewis has been involved in the Women's Movement since the late 1960s. Lewis' definition is as follows:

> *Feminism is the belief that women should be equal to men and currently they are not. It also refers to any actions, especially organised, that promote changes to society to end patterns, which disadvantage women. Feminism addresses economic, social, political and cultural disparities of power and rights.*
> (Lewis, thoughtco.com, 2017).

Furthermore, I found a fascinating statement from Hoff-Sommers, an American philosopher, included in a newspaper article written by Visser in 2016. Hoff-Sommers (2016) is stating that:

> *Feminism has been hijacked by humorless women who believe that they are constantly threatened by men. This is not only nonsensical, it is also harmful*
> (Hoff-Sommers in Visser: *Vrij Nederland*, 9th January 2016).

In the article as mentioned above, Hoff-Sommers explained her vision on feminism, that feminism is the equal treatment of men and women. It is not, as she suggested about the fact that men and women are equal, because, in her view, they are not. Feminism, according to

Hoff-Sommers (2016), has its roots in Humanism (Klaverwijden, 2010). Hoff-Sommers (2016) highlights the need for freedom, dignity and openness for all humans. However, in her view, feminism nowadays focuses on the differences between the sexes, such as accusation, repression and punishment (by men against women). Furthermore, Hoff-Sommers (2016) argues that, with their work, modern feminists regulate and criminalize sexuality. With this view, modern feminists take people back to the Victorian era (Visser, *Vrij Nederland*, 9th January 2016).

3.6.2 Feministic attention and empirical research

Olesen (2005 in Denzin & Lincoln, 2005) suggests that the current landscape of policy analysis is often quantitative and male dominated and it is the explicit role of the feminist qualitative researcher to demonstrate that qualitative research can contribute to the framing and the interpretation of policy. Furthermore, Olesen (2005 in Denzin & Lincoln, 2005) states the importance of the need for qualitative feministic research, in order to be seen from different perspectives, such as policy, law and health. Olesen (2005 in Denzin & Lincoln, 2005) underpins her view with a statement from herself and Clarke, which was published in 1999:

> *It is important to recognise that knowledge production is continually dynamic - new frames open which give way to others which in turn open again and again. Moreover, knowledges are only partial. Some may find these views discomfiting and see in them a slippery slope of ceaseless constructions with no sure footing for action of whatever sort. It is not that there is no platform for action, reform, transformation or emancipation, but that the platforms are transitory. If one's work is overturned or altered by another researcher with a different, more effective approach, then one should rejoice and move on. What is important for concerned feminists is that new topics, issues of concerns and matters for feminist inquiry are continually produced and demand attention to yield a more nuanced understanding of action on critical issues.*
>
> (Olesen & Clarke 1999: p 356 in Denzin & Lincoln, 2005: p 260).

Referring to the previous statement, van Mens-Verhulst (2001 in Klaverwijden, 2010) also determines that there is a shortage of empirical research that uses a diverse approach, proposing the need for empirical answers on women issues due to the fact that women are not identical. In the case of the current project, for example, the following questions can be asked, as to ‘Who is the actual person who has SE-AN?’, and ‘What are the strengths and possibilities of the SE-AN condition for a person suffering from it?’ and ‘What are the positive and negative experiences of a person with SE-AN?’, etc. (Hoogsteder & Sbiti 2013)[16]. In the dissertation of Klaverwijden (2010), she refers to van Mens-Verhulst (2001) that empirical research is often connected to methodological shortcomings such as the incorrect reduction of complexity, dynamics and power politics. In the explanation of the topic of this project, for example, people (mostly females) with SE-AN were often excluded from research because of the possible negative influences on the results during the testing of new therapies, which was motivated by the following reasons: SE-AN patients are regarded as vulnerable because of their appearance as thin females; and because of their persistent worries pertaining to weight, food and body shape (Touyz et al., 2013; Noordenbos et al., 2000). Researchers, who focus on the development of new treatments in ED, prefer to include patients who have experienced an eating disorder for less than one year (Rollins & Piazza, 1981) but only up to approximately four years (Gowers et al., 1994). As a result of this, the possible in-depth knowledge of women who suffer with SE-AN is ignored.

In conclusion, van Mens-Verhulst (2001 in Klaverwijden, 2010), as well as Olesen (2005) propose the carrying out of a qualitative method of research, in order to gain a better understanding of the patients’ experiences, by having the advantage of using participants who are personally involved with the topic of the research. Furthermore, this method offers a better opportunity for the explicit study of the (subjective) thoughts and experiences of the researcher (Klaverwijden, 2010).

---

[16] Van Hoogsteder M, Sbiti A (2013). Werken in de langdurige zorg, Een diversiteitsperspectief. Kenniscentrum interculturele zorg. https://www.google.nl/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=2ahUKEwiotYSEZ_gAhUJJlAKHbeaACMQFjAAegQICBAC&url=https%3A%2F%2Flegacy.vgn.nl%2Fmedia%2Fdownload%2Findex%2Fmediaid%2F52a9c640ed097&usg=AOvVaw33mEx6mzHoGoY2V-jID3lq.

Furthermore, in this section, I will examine the work of Heenan (1995, 2005), who has an in-depth interest in women with eating disorders, and is herself a female therapist and researcher. Heenan (1995) analysed the practice of a psycho-analysis group, which considered women suffering from eating disorders. In terms of this practice, Heenan (1995) described the several insights of psycho-analytic work, since the models of psycho-analysis are highly influenced by people's 'unconscious processes'. And instead of discussing the fact of being pro- or contra-feminist psychotherapy, Heenan (1995) proposed the notion of investigating eating disorders in women as socially-constructed phenomena, and as gendered expressions of distress, whilst performing feminist psychotherapy. In her later work, Heenan (2005) proposed the idea as to why women develop eating problems, and she relates these problems to the social pressures that Western society puts on them. Heenan (2005) stated that clearly *not every* female develops an eating disorder, although she reflected on the physical and psychological development in Western society and how females seem to be preoccupied with body size and shape. Conversely, current consumerism asks women to perform in typical roles as 'caregivers' and in terms of 'making things right for others' (Orbach, 1986, in Heenan, 2005). In her work, Heenan (2005) examines the emotional and physical places that Western females have to negotiate in their situation relating to 'attention', 'being thin and beautiful', 'dieting', and finally, 'consumerism and the body'. Heenan (2005) described the toxicity of Western society, and that, in the current culture, the boundaries between the private and the public are blurred. They contradict the materialistic need for, and the emotional meaning of, food and the gendered body between the psychodynamics of choice, transformation and the fear of exclusion (Bloom et al., 1994, in Heenan, 2005). Subsequently, Dolan (1994 in Dolan & Gitzinger 1994: p 4) examined the overvaluation of fatness in women relating this to fertility, where fatness represented fertility and nurture. This was seen as valuable to male relatives , who thus were led to taking care for the female family members, for example, feeding them. Hence, Dolan (1994 in Dolan & Gitzinger 1994) determined the parallel between the idealization of thinness in women, which began in 1920 and the upcoming emancipation and sexual liberation of women in Western countries (Dolan & Gitzinger, 1994).

3.7 Making a choice

In order to support and frame a qualitative research, I decided to use GT (Glaser & Strauss, 1967; Charmaz, 2006, 2008), which is suitable to guide the research question that I formulated (Crotty, 2009). This research question is as follows: *Which factors are responsible for a reduced quality of life of people living with a diagnosis of severe and enduring Anorexia Nervosa?*

Using GT enables me to look beneath the surface of the topic, and to embrace the deeper aspects and symbolism of women with SE-AN (Glaser & Strauss, 1967; Charmaz, 2006). Due to the creative strategies that are included in GT, I will determine the different concepts which are important in the quality of the lives of the SE-AN women. This knowledge can best be described as an iterative process, whereby the answers from the SE-AN women will help to develop a theoretical frame, and the data gathered will help to develop further questions for the participants (de Jong et al., 2008; Glaser & Strauss, 1967; Charmaz, 2006). GT, originally developed by Glaser & Strauss (1967), was designed as a method for qualitative research in social sciences. The method is still often used and has shown its value in nursing and health sciences (de Boer, 2011). King & Horrocks (2010) describe the method as a combination of Deductivism and Inductivism. According to Hughes (1999), Deductivism, designed in the twentieth century mainly by Popper, a British-Austrian philosopher of science, emphasizes that theories come first, and are followed by observations. In Inductivism, data is collected from observable facts, and outcomes are shaped into a theory. Philosophers like Russel, a British philosopher, and Reichenbach, a German physicist, logician and philosopher of science, adopted the principles of Inductivism (Hughes, 1999). In GT, Inductivism is displayed in a flexible research design, as a collection of data and the analysis of that data. Deductivism can be recognised in its propensity for systematic methods, for its verification with other existing theories, and finally, in the development of a new theory.

According to Glaser & Strauss (1967), GT is a constant cycle of three techniques: data collection, data analysis, and reflection. I will reflect on this cycle, which enables me to make a decision for the next step in the data collection. Data collection focuses on the development of concepts or categories. The in-depth of concepts and categories will be achieved by constantly comparing the findings. Sections of text will be compared; the first data set will be compared with the second data set; and uncovered concepts or categories relative to each other will be compared.

GT (Glaser & Strauss, 1967) aims to develop a theory, whereby the researcher uses the concept of *theoretical sampling. Theoretical sampling* is the direct search for new informants, led by previous outcomes. This empirical cycle is focused on the content and depth of the concepts or categories. In this way, a theory is developed.

In classic GT (Glaser & Strauss, 1967), the researcher seeks to construct a theory by using the philosophical insights of Inductivism and Deductivism relating to issues of importance in peoples' lives (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Since 1990, GT has developed into a more general method (Strauss & Corbin, 1998). However, since 2000, followers of Strauss have developed different forms of GT. For instance, Corbin (in Corbin & Strauss, 2008), who uses a Pragmatic/Interactionist/Feminist paradigm as a starting-point; Clarke (2005), who uses a Postmodernist paradigm; and Charmaz (2006), who uses Constructivism as a philosophical insight. In this project, the research question is, of course, pivotal, and 'leads' to the choice of the Constructivist GT method, which will be further elaborated on in Chapter 4. Nevertheless, in the Constructivist approach, Charmaz stated that her own ideas, dilemmas and demons are also considered as worthy data. It is important to clarify the origin of the meanings, views and ideas which emerge during the study, since, according to Charmaz and Glaser, this strengthens the rigour of the study (Charmaz, 2006, 2008; Glaser, 2007: p 2). Moreover, in my role as a researcher and as a nurse therapist, I *am* involved and thus influenced by the prevailing theories of SE-AN sufferers, and in terms of my daily practice; I *am* involved within the temporary constructs of the women with SE-AN. Thus, regarding my background, I made a choice to use the Constructivist GT approach after Charmaz[17]. To comply with this statement, Charmaz (2006, 2008) advises discussing one's own meanings with one's supervisors.

3.8 Summary

In Chapter Three, I presented the choice for delaying the literature research, which is synchronic within the use of the methodological qualitative social constructivist approach of the study I have presented. Next, I have elaborated on the reason for my choice of using a feministic perspective. Furthermore, I have provided explanations for the development of the methodology. I explained the ontology, the epistemology, and the theoretical perspective. The philosophical insights provided by Social Constructivism, which underpin this study, are placed against the scientific stances of Positivism, Post- Positivism and the Critical Paradigm to provide further clarity. In the following chapter, I present an elaboration of the fundamental methodological steps or, in other words, *'the research method'* (Charmaz, 1996, 2006, 2008), which I use in this constructivist study approach.

---

[17] This also contributed to my decision to write in the first person.

Chapter 4 The fundamental methodological steps of a Constructivist Grounded Theory approach

4.1 Introduction

In this chapter, I start with a definition of a Constructivist Grounded Theory approach, Hence, I underpin my choice for using a feministic lens in approaching the research question. Subsequently, I describe the method of recruitment and the sampling of the women with Anorexia, who are the participants of this project, and I also discuss the interview location. With regards to the transparency of the constructivist approach (Charmaz, 2006), I will outline each fundamental methodological step in the data processing as shown in Flowchart (2), which is located in Section 4.5.8 - Integrating findings into a theory. Hence, in this chapter, I attach several examples of data which are otherwise not being interpreted or analysed in any way. These data illustrations serve as a vehicle for demonstrating the methodology in action. Finally, I explain my choice of utilising software programmes, such as MAXQDA and Simple Mind Lite in the process of the data analysis.

4.2 A definition

Charmaz (2008) argued that grounded theorists choose or even create specific methodological strategies in dealing with data problems. Moreover, Charmaz stated that the method itself is emergent (Charmaz, 2008: p 156), and that GT itself is a method of emergence and explication, and is a systematic co-operation between inductive, deductive, comparative and interactive strategies. Nevertheless, not to be confused by the number of strategies, I decided to follow the fundamental steps of the constructivist approach, as described by Charmaz (2006). To present an appropriate elaboration of the methodological steps, I start with the presentation of a definition of the constructivist approach, as given by Charmaz (2006).

> *A constructivist grounded theory approach places priority on the phenomena of*

> *study and sees both data and analysis as created from shared experiences and relationships with participants.*
>
> (Charmaz, 2006: p 130).

According to Polit & Beck (2011), a constructivist paradigm is also referred to as a naturalistic paradigm and represents a robust alternative approach in nursing studies. A definition is given below:

> *Naturalistic paradigm: an alternative paradigm to the traditional positivist paradigm that holds that there are multiple interpretations of reality, and that the goal of research is to understand how individuals construct reality within their context; often associated with qualitative research.*
>
> (Polit & Beck, 2011: p 416).

4.3 Through the lens of Feminism

Regarding the main research question of this project, it is extremely relevant to explore the discovered categories from a feminist perspective. Nevertheless, research and policy analysis can still be placed in the context of a quantitative and a male-dominated area (Olesen 2005 in Denzin and Lincoln, 2005). According to Finch (1986, in Olesen, 2005), qualitative research may contribute to the understanding of, and the framing of, policy in healthcare. Olesen (2005 in Denzin & Lincoln, 2005) summarised multiple examples in the field of policy, for example, the framing of women's health in the abortion debate (Petchesky, 1985, in Olesen, 2005 in Denzin & Lincoln, 2005).

4.4 Sampling and Recruitment

This section elaborates on the method of sampling and the recruitment of the women suffering with SE-AN, who were the participants in this project. According to GT, the number of participants cannot be determined in advance. The process of interviewing will be repeated until the interviews do not provide any new or unique data to that which has already been collected (see also, Section 4.5.5 - Theoretical sampling, saturation and sorting (Charmaz, 2006: p 12 & 97-122). A leading question in GT is 'Will interviews provide new or relevant information and will this information guide me to new sources?' In accordance with the nature of a constructivist approach, compulsory inclusive and exclusive criteria are not used. Nevertheless, whilst focusing on the research question to ensure the findings are more robust, I exclusively focused on the women SE-AN sufferers in the attempt to give these women 'a voice' regarding the fact that they lack scientific attention as a sub group (see also: Section 2.2.5: Quality of life as seen from a feministic perspective, and Section: 5.3.4: Justice), despite the fact that, in grounded theory, it is possible to integrate other appropriate sources, such as family, friends and staff (Charmaz, 2006). Nevertheless, the issue was discussed by the supervisory team whereby it was considered to stay close to the topic of interest; the women SE-AN sufferers. The women will be recruited by the following inclusion criteria:

- Participants meet the criteria of SE-AN, that will be:
- Diagnosed with Anorexia Nervosa, > 7 years or longer;
- Participants should have received a minimum of one common treatment as usual, received from an eating disorder specialist therapist (see also: Section 2.3.2: Dutch Specialist Eating Disorder Service Units (SEDU);
- Women, > 18 years or older

At the start of the study, interviews were arranged with the women SE-AN patients, who were be selected from the patient files of the SEDU where I work (Emergis, Mental Health Institution, The Netherlands).

In the explanation of the small sample size of the eight women participants as used in this study, at the moment of recruitment, fifteen women SE-AN sufferers, took advantage of the SEDU. Considering the sample pool, all of these women met the inclusion criteria as described as above. During my research, in total, I proposed a sample of ten women to participate in my study in random order. Two women refused to participate without further explanation of their choice. Hence, after interviewing eight women, the data appeared to be saturated, hence, it was reasonable not to invite other possible women SE-AN sufferers being a participant (see also, Section 4.6.5 Theoretical sampling, saturation and sorting, and Section 6.7 Theoretical saturation.

Then, as proposed by Blumer (1969) and Lofland & Lofland (1995, in Charmaz 2008: p 162), generating a theoretical analysis requires familiarity within the phenomenon of interest, and Charmaz argues that researchers are not adequately equipped in the fit of their analysis, unless they have acquired an intimate understanding of the topic, which is strongly advocated in the execution of this project within my work force.

Hence, Charmaz (p 83, 2006) argues that the familiarity not only includes an in-depth knowledge of the studied phenomena, but, for me, it provided the possibility of reaching that level of understanding *going through* their experience; it was just this level which moved me beyond taking the same things for granted that the SE-AN women assumed. Moreover, following a constructivist stance justified my choice for studying my own patients. Nevertheless, following this stance, I was aware of the possible bias influences which could appear, and which is why I often wrote memos and discussed the topics and data in the supervisory team (See also: Section 5.2.6: Bias). Another benefit of interviewing my own patients was that it offered the possibility of taking account of the real-life circumstances, (Ionnidis, 2016). I was familiar with the interviewees, their constructs enabled me to have a completer understanding of the circumstances they are in.

Chapter 6, Section 6.2 contains a short and personal description of the patient participants and their experiences within the interviews I conducted. In this project, I focused solely on adult women, and all were a minimum of eighteen years old and older. I have chosen to only study women for several reasons. Firstly, regarding the prevalence of SE-AN (see also Section 2.1.2 - The prevalence and incidence of Anorexia Nervosa), according Smink et al. (2012), in general practice in both the UK and the Netherlands, the incidence rates of AN among males was less than 1 person/100.000 per year. As a result of this figure, recruiting male SE-AN patients might prove difficult. Secondly, I have chosen to examine the feministic stance in empirical research[18]. As described in Section 3.6, Heenan (1995) proposed the statement that in women

---

[18] Section 3.6: Feministic paradigm; Section 4.3: Through the lens of feminism; Section 2.2.4: The quality of life as seen in the context of a feministic perspective.

with eating disorders, this was a socially-constructed phenomenon, which functions as a gendered expression of distress. As referred to earlier, the use of a constructivist approach (Charmaz, 2006, 2010) was chosen, since I experience the world through the lens of a female.

4.5 Interview location

In this section, I present the rationale for the interview location. The choice of a location for conducting the interviews may be an important issue, since the environment may influence the confidentiality between the interviewees. For this reason, the women were allowed to choose the interview location. Furthermore, I offered them the opportunity to conduct the interviews either by telephone or face-to-face. By offering these alternatives, the women were given the opportunity for the interviews to take place in their natural environment if that was a more comfortable option for them. Although, it is recognised that interviewing the women in their own environment might be helpful in reducing a potential power imbalance between me in the role of researcher and the interviewees (May, 1993 in Howarth, 2012). Almost all the participants preferred the option to conduct the interviews at the SEDU in my workroom, except for Sandy. Her interview was carried out in her own environment by means of ‘Skype’. Sandy preferred the option of using Skype for the interview as she was not able to travel to the SEDU because of her poor physical condition. In the event, Sandy she also said that she benefitted from this interview method because she was able to stay in her own, familiar environment where she felt safe. Being comfortable in the environment was important as it allowed the women participants to open up because they feel free to do so (Howarth, 2012). Hence, she became enthusiast by showing her pet dog through the camera; this was an unexpected, further benefit of using ‘Skype’ since this dog[19] would never had the permission to visit the SEDU. The other interviews were all conducted in my workroom as the preference of the

---

[19] In the Netherlands, certified assistance dogs only have the permission to access public buildings during the accompaniment of their owners.

women themselves. Interviewing the women at the SEDU location was the most agreeable place for the participants that made use of the in-patient setting at the time of interview. Other women gave no explanation for their choice of the interview location. Nevertheless, it did not appear to be problem for them, most likely because they were familiar with the building, my workroom and me.

4.6 The methodological steps in data processing: 'dilemmas and demons'

In GT, many scholars have developed diverse strategies and guidelines, which refer to the coding process (Charmaz, 2006; Goulding, 2005; Partington, 2002; Patton, 2002; Strauss & Corbin, 1990,1998; Glaser & Strauss, 1967 in Evans, 2013). This development of different strategies seems to be responsible for an on-going debate between GT researchers. Some researchers even choose to combine qualitative and quantitative data in GT. Naturally, the use of such a method is not precluded but, as Evans claims, it can adversely affect the credibility of the data and blur the findings (Evans, 2013). On the one hand, it is important not to be too rigid about the coding process, as this might place limitations on the researcher's competence in the completion of the project (Glaser, 1978 in Evans, 2013; Charmaz, 2006). On the other hand, Miles, Huberman & Saldana (2013) describe a process of clear steps, divided into the search for patterns, clustering, metaphors and the amount of appearing phenomena. Miles et al. (2013) clarify the method of counting the appearing phenomena in order to verify a hypothesis. This is an understandable method, which is often used in deductive analysis and is suitable in positivistic approaches. Furthermore, Miles et al. (2013) propose the idea of building "a logical chain of evidence" (Miles, Huberman & Saldana, 2013: p 290) by searching for the logic between the variables. As seen from the point of view of Charmaz (2006, 2008), this method might be considered an obstacle to 'keeping an open mind', since it challenges the researcher into drawing conclusions too quickly. Subsequently, Miles et al. (2013) also pose the question of researcher bias, as the researcher may have their 'own agenda' and have ‘personal demons’, which, in turn, may skew the transparency of the study in terms of the presentation of the fieldwork and the analysis. Conversely, according to the constructivist approach (Charmaz, 2006, 2008), researchers’ own ideas, dilemmas and demons can be seen as worthy data, as long as the origin of those meanings, views and ideas are clarified. With this in mind, Charmaz (2006, 2008) advises researchers to discuss their own meanings with their supervisors, and she suggests the possibility of a research peer group. However, Gynnild (2011) argues against switching between the different strategies of data collection for the different GT methods.

As a result, I have closely adhered to the constructivist approach, and thus, I followed the steps as presented in the work of Charmaz (2006), who sets forth a clear process through the strategies. This creates a robust and reliable approach to the analysis and, therefore, this strengthens the trustworthiness, and thus the validity, of the developed theory.

To clarify the steps in GT, I have summarized each step separately, with each step representing a part in the data process and will be elaborated per section in this chapter. The steps are, however, logical and they strengthen each other, and thus, each separate step cannot be provided as an individual method Together, they form the constructivist GT according to Charmaz. In the visualisation of the process, I have added a flowchart of the constructivist approach (Charmaz, 2006). (see Figure 8 – after Charmaz, 2006: p 11).

4.6.1 Sensitizing concepts and general disciplinary perspectives

Glaser states that “*[a]ll is data*” (2007). With this statement, Glaser proposes that there is no such thing as bias, either objective or subjective, but that data is what the researcher receives. Charmaz (2006) concurs with this quotation, and argues that everything the researcher learns in the research setting or in scrutinizing the research topics, can serve as data. Hence, Charmaz acknowledges the co-construct of a theoretical understanding of people’s experiences and of their personal interpretations in a partnership with the researcher and the topic of research (Singh & Estefan, 2018). In the current project, I am concerned with the women SE-AN sufferers, and, therefore, *sensitizing concepts* will be used. In her work, Charmaz (2006) refers to Blumer (1969), stating that:

> *[g]rounded theorists often begin their studies with certain research interests and a set of general concepts. These concepts give the research ideas to pursue and sensitize the researcher to ask particular kinds of questions about the topic of interests.*
>
> (Charmaz, 2006: p 16).

The *sensitizing concepts* (Figure 4.1) that I have used in this study are developed out of a global exploration of existing theories of eating disorders, specifically SE-AN, and by combining my personal experiences (Chapter 1 - Introduction; Chapter 2 - Background). Furthermore, in order to judge the ethical quality of the guiding questions, I presented the *sensitizing concepts* to the supervisors of the current study, to the ethical committee of the University of Central Lancashire (UCLan), and to the Erasmus University, Medical Centre (ErasmusMC). Charmaz (2006) argues that, in looking at the data and in listening to the interviewees, *sensitizing concepts* are a starting point for the development of ideas, rather than a limitation in the interviews. In my interviews, I have not used a rigid questionnaire of *sensitizing concepts* (the guiding questions), rather I was guided by the development of the conversation with the interviewees. It is possible, therefore, that I pursued other topics, because the women defined them as important.

The Sensitizing concepts as used in the interviews
Opening question: *What is your perception of life, as influenced by the diagnosis of Severe and Enduring Anorexia Nervosa?*

Possible prompts:

- How does the diagnosis affect your day-to-day quality of life?
- If you recovered, how different would your life then be?
- Can you give me an example of a time when you felt that your quality of life was affected by your diagnosis?
- Do you notice that other people make allowances for you?
    - What are these allowances?
    - What difference do these make?
- Can you remember a time, whilst having AN, when you were happier than you are now?
    - What was different?
    - What would make your life better right now?

Figure 4.1: Example of Sensitizing Concepts, as used in this study

4.6.2 Data collection and coding

The next step in this study is the conducting of the interviews with the women with SE-AN. In the process of the data collection and the analysis, Charmaz (2006) refers to Glaser & Strauss (1967), Glaser (1978) and Strauss (1987 in Charmaz, 2006), and proposes that the data collection is a simultaneous engagement with the data analysis, by means of using the constant comparative method at each stage of the analysis (Charmaz, 2006: p 5). Charmaz (2006) stated that the data collection method could be seen as a tool, not as a rigid guide to follow. Next, Charmaz (2006) recommends placing the gathered data into their relevant situational and social contexts, which makes a much better starting-point for me as the researcher in terms of analyzing and understanding the findings. As seen from this particular point of view, I considered it as important to write memos of the situations, the thoughts and the perspectives of the SE-AN patients (see also Section 4.5.2.4- Data collection: memos) (Charmaz, 2006; 2008). In illustration of this step, I made notes during the interviews, and I also wrote notes as I worked, as a reminder to refer to various topics and contexts which were important to mention during the interviews. Furthermore, during the writing of the verbatim transcripts, these notes assisted me in focusing on specific topics.

4.6.2.1 Data collection: initial coding

At this point, all the spoken data collected is transcribed into verbatim transcripts. The first phase in the data-analysis is *initial coding*. As with Strauss (1987, in Charmaz, 2006) and Corbin (2008), verbatim records were carefully read and accredited with code words. This made it possible for me to use the initial coding to differentiate and explore any theoretical possibilities within the data (Charmaz, 2006). Furthermore, this step supported me in moving forward and creating possibilities for decision-making in the research process. With this, I was able to distinguish the important data at a later stage in the research. Likewise, this initial coding allowed me to see the *"gaps in the data", and "discovering these gaps is a normal step in the analytic process"* (Charmaz, 2006: p 48). It is, therefore, the case that GT advocates the importance of the constant comparative method (see also Section 4.6.2.2). However, it enabled me to search for data, in order to bridge the gaps. At this stage of the research, comparing data helped me to generate the properties of each initial theoretical category. During the initial coding, I have used four leading questions (Glaser & Strauss, 1967; Glaser, 1978). In illustration of the method, an excerpt of a memo is included below (Memo 1), which explores the analysis of the data set of Sarah, which was guided by the four leading questions:

- *What is this data a study of?*
- *What does the data suggest? What does it assert?*
- *From whose point of view?*
- *What theoretical category does this specific data indicate?* (Glaser, 1978, in Charmaz, 2006: p 47).

Memo 1: Exploring the analysis of the data set of Sarah
The data studies the effects of SE-AN in a woman who attempts to live her life as normally as possible. The 'routine' of her daily life can be described as: having a relationship, friends, and family and being a member of a musical association in her leisure time. **The data suggests a focus on the loss of self-determination***,* what can be seen as the loss of freedom to choose what she wants (or not); others make decisions for her. It feels like a burden but the participant isn't able to change this opinion.

Then, **in the point of view of Sarah,** the AN has damaged the relationship between her and her parents and brothers. The relationship has changed into a rational relationship between all parties. It is functional for practical help in problems such as, financial support, or transporting requests. For Sarah, it feels like a decision in the communication with her family members, driven by the motive to protect her, and her parents against the emotional and painful effects of having a child with an ED.

Also, the data suggests the power of the ED: Regarding the influences of the ED on Sarah, whilst studying and combining an ED treatment. That combination seemed to be unfortunate because both (study and ED) asked for her full attention. Therapy did not gave her relieve, or a solution, but then, the ED felt like a third party, also appealed her attention. Finally, Sarah wasn't able to work or study anymore, or with her ED condition which led to other complaints; she was burned out which made her more dependent on others and moreover, her condition at that moment, strengthened the ED.

What early theoretical category does Sarah's data indicate?

- Talking through the eating disorder (communication, suffering)
- Others are taking distance by using a formal form of contact (communication, suffering)
- Experiencing a strengthening of the eating disorder (suffering)

Memo 1: Excerpt of data analysis of Sarah

Charmaz (2006) describes three different coding methods as possibilities in the approach of the initial coding. Firstly, the 'word-by-word' coding, secondly, the 'line-by-line' coding, and finally, the 'incident-to-incident' coding. In this project, I utilized 'line-by-line' coding, as it had the benefit of scrutinizing the data more quickly, and it supported me in being able to stay close to the data and construct initial codings (Charmaz, 2006: p 50). As a technique, the line-by-line coding literally requires the naming of every line of the written data (Glaser, 1978, in Charmaz, 2006). Working with this method, I discovered new ideas in the analytical process, whereby it was possible to discover detailed observations and the nuances of them. Figure 4.2 provides an example of line-by-line coding, as utilized in this study:

Line-by-line coding: code name: defining craziness
"I am not normal, I do things which aren't healthy, I walk like a fool, that's why I think I don't have the right to talk about it. I am not a holy person". (Mariah: L221)

Figure 4.2: Example of a Line-by-line coding: Defining craziness

Next, I used 'incident-to-incident' coding (Charmaz, 2006: p 53), which worked for me as a tool in analyzing the data. With this technique, I compared several incidents, without any knowledge of the context. The technique yielded the discovery of the early theoretical groups (see, Section 6.4: The process of initial coding). For instance, in my search, two seemingly-unrelated situations emerged, which, by comparing the two, I was able to conclude that I could place them in the same early category, due to the resemblance that emerged. An example appeared in the discovery of the early category of ‘suffering’, using incident-by-incident coding, and is shown below (Figure 4.3: incident-by-incident coding: Defining guilt).

Defining guilty feelings through incident-by-incident coding in the presentation of the early category of suffering: Defining guilt
“My focus is eating, and exercising. Once; and it is always when I really exhausted, I cannot stand it when somebody is exercising. An example, if somebody goes for a stroll, and I cannot go, I feel myself so very guilty. I feel guilt by lying on the couch, or in bed. Like, someone else is doing something I needed to do. I have to carry that load, I have to make it possible for the other that he, or she can take some rest.” (Mabel: L86)
“And when I look at my life, it costs me a lot, I have a very bad relationship with my parents, it is really worse. But also, I cannot work, even though; I finished my study, which took me a lot of effort, and actual pain. But still, I cannot work; I am not a person who counts in our society. I feel outplaced. For sure when I look back to the treatments I experienced, it is for sure that the several treatments generated this status. Every time, I feel myself an outlaw in our society, and it becomes more and more difficult to fit in.” (Sarah: L33)

Figure 4.3: Example of the incident-by-incident coding: Defining guilt

In the example figure above, the two apparently-different situations of two women are examined, though the collective code for both excerpts is ‘guilt’, which emerged when scrutinizing the data.

4.6.2.2 Data collection: the constant comparative method

In Grounded Theory, the constant comparative method (Glaser & Strauss, 1967) is used. According to Glaser & Strauss (1967), the method ascertains differences and gives the possibility of making comparisons at each analytical level. Thus, data is compared to reveal differences and similarities. For example, in this project, I compare situations, statements and incidents in one interview, and working towards this process, I compare earlier findings with findings that have emerged from other data sets and personal memos. In this process, it is important not to reject my own personal thoughts, even if they do not mirror the data directly.

Charmaz (2006) advocates that I can indulge my ideas with this process, since it might be possible to form new ideas, and to check my own data.

In addition, combining the techniques of coding can give me insights into my personal thoughts, beliefs and my *'coloured'* perceptions relating to the topic of interest, and indeed, as I have treated people with eating disorders for a number of years, I have to take account of my own personal view relating to the topics (Charmaz, 2006). These insights can be extremely valuable, as they force me to think about the data that emerges that may differ from the women's points of view. Thus, Constructivism is clearly seen in this research, creating the view that earlier ideas may still be worthy. As a result, I created a transparent approach where I viewed and coded the data first, and then, both the data and my initial coding was scrutinized by my three supervisors during three days in April 2018. This intense level of scrutiny and debate ensured that the data 'spoke for itself' and that the interpretation of the data was reliable.

4.6.2.3 Data collection: 'in vivo' codes

'In vivo' codes are the means of assigning labels to the data. In this case, it is indicative of the participants' 'knowings and understandings'. The 'in vivo' codes express significant meanings. Alternatively, they are innovative term, given by the participants, which reflect their perspectives (Charmaz, 2006: p 55). 'In vivo' codes refer to the special terms the women use. For example, as in the next quotation, given by Sophie:

> *"I thought I was too fat".*
>
> (Sophie: L96).

According to the topic of the project and relating to thoughts about eating, weight and being convinced that they are too fat, the quote above gives an idea of the type of 'in vivo' codes that are found in the narratives of this project.

4.6.2.4 Data collection: memos

As Charmaz (2006) claims, *'[i]n the process of research it is important to take an analytic break, so stop and write informal analytic notes'* (Charmaz, 2006: p 72). I defined this quotation as important, as it caused me to realize the effect of an analytical distance. In turn, this supported me in my decision-making in terms of: '*What am I looking for?*' and '*Am I still on the right track?*'. The notes I made are referred to as memos (Glaser &Strauss, 1967; Charmaz, 2006). Throughout this project, I wrote memos, containing my thoughts and the ideas which I developed in the application of this study. The memos gave me an insight into my process of decision-making, which, together with the data collection and the observations[20] which I collected due to practice, led to a final theory. Hence, it is note worthy to explain the observation technique as used in this study, which is the reason for elaborating the concept in the following section. Furthermore, the memos supported me in the data analysis and the development of the codings and the categories, with an explanation of this given in the following sections. Charmaz (2006) strongly advocates that memo writing can be utilised as a tool in the comparison of data, in order to further process the data collection, and throughout my project, I discovered the worth of this tool. (see, for example, Memo 2 below.)

The most important part of memo writing is to write down one's thoughts and to store these electronically, in order to support the researcher in the thought process (Charmaz, 2006: Chapter 4). During this study, I used my smartphone to store short messages and notes in preparation for more elaborate versions of the memos, since I almost always have my phone with me wherever I go. With this, I was able to write down spontaneous thoughts, mostly provoked by work situations, and later processing them, and sending them for storage on my personal computer, as these are my reflections of a work situation. These spontaneous memos were particularly valuable, as they contained my thoughts and ideas related to the investigated topics. Moreover, in order to monitor my insights, I also sent these memos through to my supervisors, who were then able to give me feedback. With this, I ensured the openness of my

---

[20] In this study, I did not use observation as a separate data collection method.

project, which, in turn, would help increase the validity of the findings. In addition, the feedback I received from my supervisory team provided me with a deeper insight concerning the data. (see, for example, Appendix 7: Example of email correspondence with the supervisory team at UCLan.)

Memo 2: Stigma, dignity, dependence

March 2017

Today a mother came to see me, she has brought her daughter with her, she (the daughter), could not stand on her feet anymore.

The daughter is one of my patients, aged 43. I know her well, for at least for 7 years. She often made use of the in-patient setting during the past years. This woman, diagnosed with AN, the purging type, has suffered for a long time with a severe condition. She has suffered from AN since her adolescence. And today, she literally clung to me and cried.

She explained to me her intense fear of dying. However, death was near by, she felt she was loosing the control if nothing happens.

She explained to me shortly what had happened in the past few days. She told me she had visited a general hospital because of frequently losing consciousness. Nevertheless, the doctors sent her away, with the message that they were not able to help her. And then, this woman lost her dignity and begged the doctors for in-patient help.

Hence, that particular situation gave her the experience of intense fear. After being sent away from the general hospital, she went home and she experienced a few severe anxious hours. The only thing she could do was to contact our SEDU, even a few times in the middle of the night.

Those telephone calls were made in a state of complete panic and made a serious impression on the nurse of duty.

The feeling that she was dying, as soon as she closed her eyes, overwhelmed her with fear.

Key words

1. Dignity (she lost her dignity by begging doctors for help)
2. Rejection (the contact with doctors in the general hospital), does SE-AN lead to stigma?
3. Dependence (of care workers on the SEDU - on mother- on me- on the AN.
4. Dependence versus independence. (I know this woman, AN gives her independence, AN is the only ‘friend’ who will not abandon her)
5. Anxiety

Physical and psychological conditions

- 27 kilos / BMI 8
- Severely disturbed potassium and phosphate levels
- Deeply miserable and anxious
- Mother was panicking because of the likelihood of the loss of her daughter

Question

What is dependence versus independence, what are the properties of dependence and is there a connection with stigma and the loss of dignity?

Memo 2: Example of a memo excerpt, as used in this study.

The memo above was written in the early stage of the project, and provided me with further insights relating to the question of dependence. However, later in the analysis, the exploration of this phenomenon appeared less important, and for this reason, I did not elaborate further on the issue of dependence.

4.6.2.5 Data collection: observation method

In this study, I did not use observations as a separate data collection method. The observations as such, appeared as a method of reflexivity of my personal thoughts whereby my work experience functioned as a source of it. My background and thus the observations provided the memos of critical insight regarding the topics as discussed in the interviews. Then, the observations enabled me to look for a deeper understanding of the women's constructs. As Charmaz (2006, p 3) stated; data is gathered through observations, interactions, and other materials referring to the subject of research, this statement directly supported my personal experience which I had built regarding to my topic of research. Thus, I consider the observations of high importance in nourishing the memos as used in this research.

4.6.2.6 Data collection: focused coding

The next phase is 'focused coding', a definition of which is given by Charmaz:

> *Focussed coding means using the most significant and/or frequent earlier codes to sift through large amounts of data. Focussed coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely.*
>
> (Charmaz, 2006: p 57).

In this process, multiple code words will be selected in order to study larger data files in the discovery of the underlying processes. This process can lead to a better understanding of the *sensitizing concepts*, which were formulated at the start of this data process. However, in the development of a constructivist theory, it is not simply making a new step in the data processing, but as Charmaz (2006) stated, it is possible that I will have to go back to the techniques of the initial coding. Especially when a moment of *'Now I understand!'* arrives, this might also be the moment when Charmaz (2006) requires me to go back to restudy earlier data in the exploration of the topics, which have not as yet been discovered at an earlier stage.

4.6.3 Theoretical coding

In theoretical coding, the codes I have selected in the previous phase of focused coding will be refined. In 1978, Glaser introduced this phase to conceptualise "*how the substantive codes* *may relate to each other as hypotheses to be integrated into a theory"* (Glaser, 1978, in Charmaz, 2006: p 63). In other words, theoretical codes allocate possible relationships between the categories, as they are developed during the focused coding. For this process, I decided to use the 'coding family' as developed by Glaser (1978), due to the flexibility of this approach (Charmaz, 2006). Glaser (1978) developed the 'Type C coding family', which stands for 'causes', 'contexts', 'consequences', 'conditions' and 'contingences'. Later, Glaser expanded the 'Type C coding family' into a larger frame with eighteen subcategories (Böhm, 2004). However, in this project, I chose to use the 'coding family' matrix in order to frame the findings without being too rigid about it. In the current project, using the coding family appeared to be useful, as it allowed a loose organisation of the findings. I made this decision due to the process of analysis, whereby I discovered similarities between the 'coding family' and the earlier strategy I had developed. These similarities arose during the initial coding process, which I called a 'group', in order to deal with the large amount of data. (see, for example, Diagram 1: example of conceptual mapping[21]). The next stage was developing the theoretical codes, which was useful to interpret the general context in which the phenomena are observed in their natural environment (the social worlds), which is what makes the data evident and useful in this project. In terms of my project, theoretical coding and axial coding were used in simultaneous processes.

4.6.4 Data collection: axial coding

Regarding the methods of data collection and analysis, Corbin & Strauss (1998 in Charmaz, 2006) advocate the implementing of axial coding. Charmaz provides the following definition:

> *Axial coding relates categories to subcategories, specifies the properties and dimensions of a category and reassembles the data you have fractured during initial coding to give coherence to the emerging analysis.*
>
> (Charmaz, 2006: p 60).

Thus, axial coding illuminates the development of an important category, which appears at an early stage of the research. The frame below (Figure 4.4) illustrates the coding paradigm in

---

[21] Chapter 6: Data analysis, Section 6.4: The process of initial coding, Diagram 1: example of conceptual mapping.

social research questions (Figure 4.4: Coding paradigm in social research, after Böhm, 2004). I have used this frame several times during the constant comparative analysis to define and frame the findings which have been developed, and in determining their properties and the dimensions of the categories that have been developed in process. Nevertheless, Charmaz (2006) is not entirely positive regarding the use of the technique and illuminates both perspectives. Axial coding might be helpful in strengthening the analytical power, but it can overshadow the data with the technological influences of the method. In the worst case, it is possible that the developed theory might be cumbersome, as it compresses the findings, and which, therefore, the developed theory can be influenced by the technical operation of axial coding (Robrecht 1995, in Charmaz, 2006). In this project, theoretical coding is entwined within the axial coding process. Böhm (2004) stated that the axial coding usually occurs between the major analytical steps, and is processed in the middle of, or at the end of, the analysis. This contributes to the inductive process in GT, (Glaser, 1992; Charmaz, 2006) and to the iterative process of data collection, analysis and comparison, which are the basics in the development of meaning to the phenomena (Strauss & Corbin 1990, 1998, in Vickers, 2016). Thus, this technique appeared as the opposite of the deductive methods, which has its roots in the testing theory and the hypothesis (Charmaz, 2006). In axial coding, short extracts of the texts are related to larger parts, or even to the whole text (Böhm, 2004). According to Glaser (1978) and Strauss & Corbin (1990), axial coding has proved its value in the explanation of the relationships between the categories, giving meaning to the social actions.

Although Charmaz (2006) stated that grounded theorists are led by flexible methods and guidelines for their data collection and analysis, and that those guidelines do not offer rigid methods, but instead a set of heuristic devices, such as thinking strategies and principles, I decided to embed the axial coding techniques by the elaboration of certain patterns of data in the management of the categories.

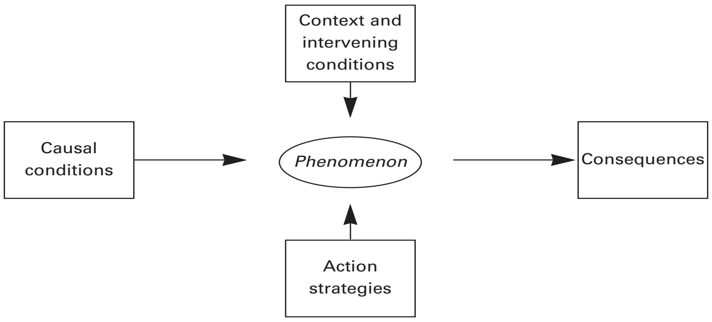


Figure 4.4: Coding paradigm in social research (Böhm, 2004, in Flick et al., 2004: p 272)

4.6.5 Theoretical sampling: saturation and sorting

The next phase is *theoretical sampling* (Charmaz, 2006). In this project, I conducted the theoretical sampling process until no new categories arose. According to Charmaz, theoretical sampling refers to *"[s]eeking pertinent data to develop your emerging theory. You conduct theoretical sampling by sampling to develop the properties of your category(ies) until no new properties emerge"* (Charmaz, 2006: p 98). With this, the constant cycle of three techniques is observed, which are data collection, data analysis, and reflection. In this project, I constantly reflect on this cycle, which is helpful in the decision-making process, in terms of the next step in the data collection. Subsequently, the data collection is focused on the development of concepts or categories. The constant comparison process resulted in the emergence of various concepts and categories. Thus, in this study, extracts of texts, words, or situations were compared. The first data set was compared with the second data set, and the concepts or categories discovered that were related to each other were also compared. Grounded Theory (Glaser & Strauss, 1967) aims to develop a theory, and thus, I use the *theoretical sampling* technique. *Theoretical sampling* also provides a direct search for new participants, which is led by previous outcomes. In this project, I included the addition of two more women SE-AN sufferers, following the theoretical sampling of the first six interviews. In this way, an empirical cycle was realized, which focused on content and the in-depth exploration of the concepts or categories.

Charmaz (2006) argues that the place in research for conducting theoretical sampling is clearly stated, in terms of the dependence of the development of the findings (the categories). For example, if the development of some preliminary categories are needed at the beginning of the research, the theoretical sampling can be used as a tool to clarify, to check and to qualify the boundaries of the categories. However, further into the research process, theoretical sampling helps to clarify the links between the various categories. Thus, in carrying out the theoretical sampling, it prompted me to turn back to previous data and to previous interviewees to seek possible answers in order to understand and elaborate on the meaning of the categories. As a result, I have done this frequently during the data processing.

4.6.6 Saturation

A short explanation of saturation in GT follows. Saturation is when no new information can be added to the categories. Thus, any fresh data does not provide me with any further new insights (Charmaz, 2006). Furthermore, Charmaz (2000, in Guba & Lincoln, 2005: p 527), referring to Morse (1995), criticised the concept of 'saturation', by posing the following question: *"What does saturation mean, and for whom?"* (Charmaz, 2000, in Guba & Lincoln, 2005: p 527). Morse (1995) defined the concept as follows: *"Saturation is operationalised as data collecting until no new information is obtained"* (Morse, 1995 in Charmaz, 2000 in Guba & Lincoln, 2005: pp 527-528).

Furthermore, Morse (1995, in Charmaz, 2000, in Guba & Lincoln, 2005) illuminates the fact that researchers claim the principle of saturation in social justice studies, where saturation is the analysis of very small samples of data. And it is precisely this method, which increases the credibility of qualitative data in GT. This statement is underpinned by the following argument, whereby grounded theorists propose that a small sample, for instance, conducting a small study, might influence the credibility of the findings of a research project (Glaser, 1992, 2001; Stern, 2001, in Charmaz, 2006).

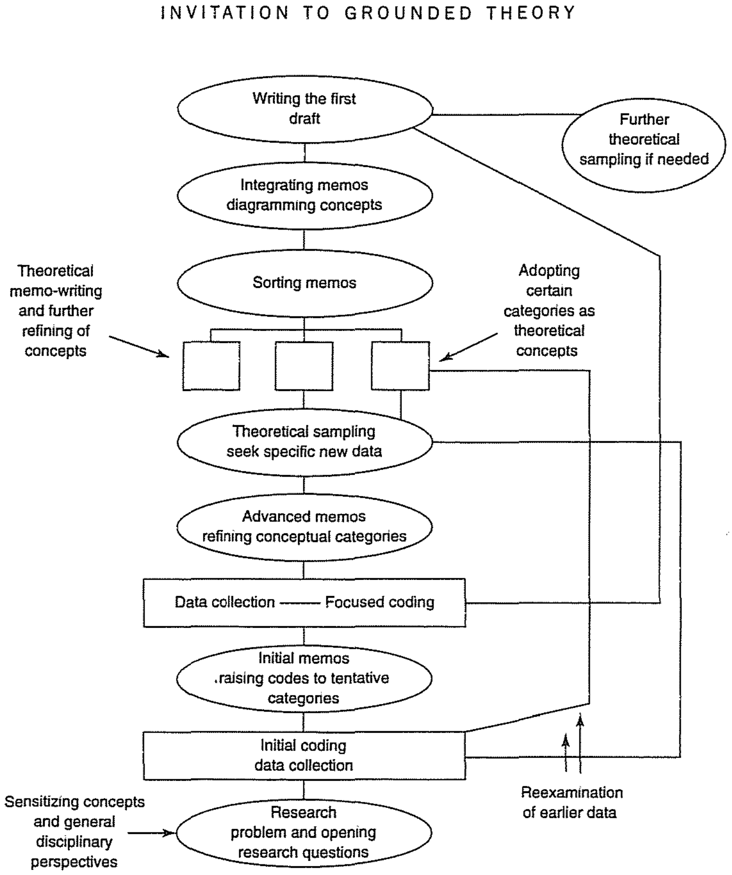
4.6.7 Sorting memos

According to Charmaz (2006), memo sorting is the integration of memos into the theoretical categories. Nevertheless, sorting memos is a continuous process, which starts at the beginning of the study. In her work, Charmaz (2006) advises clustering the memos that have been written during the iterative process. This action supported me in gaining an overview of the work, of the subjects and of the content. During the project, I have clustered related material together, in order to develop and connect ideas, concepts and categories, by preparing several 'maps' on my personal computer. Other material, such as paperwork, I stored in boxes.

4.6.8 Integrating findings into a theory

The next step was performing the data integration. This process requires the ordering of all the memos into categories. Charmaz (2006) argues that the researcher decides how the memos fit together best, in terms of strengthening each other. In the attempt to deal with my memos, I chose to conceptualise them into work documents, and in doing so, I created an ordered version, which I was able to consult in my search for robust data concerning the next step of my research: writing the draft version of my study. After this process, I integrated the literature findings, with the aim of locating, evaluating and defending the current findings of this project (Charmaz, 2006), which will be presented in Chapter 11, the discussion chapter. Nevertheless, according to the methodological steps of the constructivist approach, the findings chapters may also contain some influences from the literature. The introduction of the literature findings are not problematic and are in line with the philosophical stance of this constructivist approach, providing the initial findings are firmly 'grounded' in the data (Charmaz, 2006). Thus, extant literature findings are added to address the research questions. Hence, literature findings function as a tool to develop and clarify ideas for theoretical maturation. Though, extant literature is carefully chosen (see Section 6.8: The literature review method, and Chapter 11: Discussion of findings).

In the next illustration, I demonstrate a brief overview of the methodological steps of a constructivist approach (Flowchart 2).



Flowchart 2: Flowchart of The Grounded Theory Process (Charmaz, 2006: p 11)

4.7 MAXQDA

In 2014 and 2015, at the University of Applied Science in Utrecht, in the Netherlands, I was professionally trained in various aspects of scientific research in order to improve my research skills. During the course, attention was also given to the process of qualitative analysis, which can also be carried out more traditionally by using index cards and colour indexing. Alternatively, it can be conducted by using particular software in order to support the researcher in the analysis of qualitative data (Weitzman, 1999, in Berger, 2009). The studies which were examined demonstrated the large number of researchers who report the benefits of working with software packages in projects (Berger & Rosenberg, 2008; Liebow, 1993, in Berger, 2009).

To provide such accuracy, I decided to purchase supportive software in preparation of working through a large body of data, despite the fact that, at the start of this project, I could not have imagined the actual amount of data that would be involved. This was especially the case since, in referring to Charmaz (2006), the search for new data stops when the point of saturation is reached, and therefore, this was a possibility that I had anticipated. In one of the supervision meetings, several options for using software programs were discussed, with particular attention given to the pros and cons of using the programmes MAXQDA and ATLIS.ti, and conversely, the idea of using no software data programme at all. A search on the internet (Forum Qualitative Research; Kwalon[22]; Evers, 2009) provided me with a large number of researchers who had commented on using software programme. Li (2014), for example, summarised the notable points of the seven main software packages, including MAXQDA. Furthermore, Li (2014) offered to explain which software program is the best fit for which methodology and why. Li (2014) concluded that learning from training manuals was useful in optimising the utilization of these programmes.

A new search on the internet comparing ATLIS.ti and MAXQDA brought me a personal preference for MAXQDA, due to the several clear tutorials. I decided to purchase the program and, in connection with it, I have also attended a training day, guided by Mrs Evers at the Erasmus University of Rotterdam, in order to get more familiar with the program (maxqda.com/workshoptrainer/jeanine-evers). Hence, during analysis, I used the MAXQDA program selectivity, I mainly used Microsoft ® Word (Microsoft ® Word for Mac 2011, version 14.7.3) for my analysis. Nevertheless, all data was stored in MAXQDA on my personal computer, and it was only accessible to me by using a secure password.

---

[22] https://www.tijdschriftkwalon.nl/inhoud/tijdschrift_artikel/KW-14-2-13/Over-kwalitatieve-data-analyse-valt-nog-veel-te-schrijven

4.8 Simple Mind Lite

In the analysis of a constructivist approach, many initial codings, and subsequently, theoretical codings and findings emerge. To get a quick and broad overview of the findings, I chose to utilize the technique of conceptual mapping in the different phases of my research, where I was able to cluster the findings into a diagram. Therefore, I chose a simple, easy to use, and free mind map program, which was compatible with the Mac computer, and which was able to configure the colours as used in the MAXQDA program.

4.9 Summary

In this chapter, I have given a definition of a constructivist Grounded Theory approach. Firstly, I elaborated on, and underpinned the method for, the choices made in the sampling and recruitment of the women SE-AN sufferers and also determined the interview location. Furthermore, I have given a brief explanation of the importance of using such data strategies and guidelines, as developed in GT. Hence, I have worked out in detail each fundamental methodological step in the data processing, according to the constructivist method of Charmaz (2006). Finally, I explained my choice for using the MAXQDA and the Simple Mind Lite software. In the next chapter, I elaborate on the reliability of the GT study.

Chapter 5 Trustworthiness and ethical underpinnings of this GT Study

5.1 Introduction

In this chapter, I elaborate on the trustworthiness and the ethical underpinnings of this study. Furthermore, I explain the credibility in general, as used in a qualitative constructivist approach. In addition, I clarify the concepts of reliability and validity (Guba, 1981; Chiovitti & Piran, 2003; Coony, 2011) in order to make the findings more robust. The concepts as such are very much related to the constructivist approach by Charmaz (2006, 2008). Finally, the concepts of bias, the ethical considerations, the confidentiality, the anonymity and the funding/sponsorship will be discussed.

5.2 Credibility of GT

Every piece of scientific research is dependent on the status of the credibility and the quality of the study itself. Although there is consensus in conducting of quantitative research in terms of using established measures to achieve credibility, which relate to the criteria of reliability, validity and generalisability (Whalley Hammell, 2002), there is no such agreement in the carrying out of qualitative research. This variety of opinions has its roots in the several philosophical stances used in both qualitative and quantitative research methods. Thus, although quantitative studies are concerned with objectivity and the verification of it, qualitative studies are more associated with the subjective, interpretative perspectives of the individual (Whalley Hammell, 2002). This stance has led to a general agreement that, in judging the credibility of qualitative work, it is using the criteria which are most appropriate to the fundamental principles of the approach that is best (Morse et al., 2002). Patton (1999) argues that to strengthen the quality, validity and credibility of qualitative work, it is important to properly match the methods to the empirical questions posed, and not to create one general single methodological approach for all problems. Charmaz & Bryant (2007, in Silverman, 2011:

pp 291-309) discuss the credibility of GT, and how the explicit strategies of the GT method contribute to the development of the method itself and thus to its credibility[23]. An opposing view is offered by Charmaz, who refers to Glaser's criteria of fit, work, relevance and modifiability in reproducing the data, which causes the constructivist nature of the qualitative method (Glaser, 1978, in Charmaz, 2006: p 182; Denzin & Lincoln, 2005: p 24). Charmaz (2006) organised her judging criteria for a constructivist study, which accommodates the aspect of trustworthiness, and are partly based on the principles of Guba (1981), and which are summarized below:

a) Credibility - *the internal validity, how congruent are findings?*
b) Transferability - *the external validity - can results be applied to a broader population?*
c) Dependability - *the reliability - do similar results appear when this project is repeated?*
d) Conformability - *the objectivity - do I take account of my biases?*
(Guba, 1981).

The criteria of Charmaz (2006) overlap with the values of Guba (1981) and are developed in the following sections and summarised below:

1) Credibility
2) Originality
3) Resonance
4) Usefulness

Starting with an explanation of credibility, this is the method utilised to strengthen the credibility in a constructivist GT study (Charmaz, 2006). It refers to how the complete research process, including the literature review, is *conducted*. Thus, the credibility of the study is dependent on several techniques as described in the previous chapter (5). These techniques are as follows:

---

[23] Chapter 5: The fundamental methodological steps of GT according to Charmaz.

- The frequent debriefing sessions with a senior researcher [24], (i.e. the project supervisors) (Charmaz, 2006; Chiovitti & Piran, 2003). In response to this, I conducted debriefing sessions on a monthly basis, by using Skype. Furthermore, a 3-day visit with the whole supervisory team was conducted in April 2018, in order to scrutinize the data with the aim of making the findings more robust.

- Any credibility concerns were noted by the implementation of a logbook and by means of the memos [25] (Charmaz, 2006; Chiovitti & Piran, 2003). To comply with this requirement, and in addition to the memo writing, which has already been discussed in the previous chapter 4, Section 4.6.2.4. I used the opportunity of keeping the logbook, since it was built into the MAXQDA program, whereby I had an excellent overview of the various activities during my research.

The discussion of the data with the participants (Charmaz, 2006; Chiovitti & Piran, 2003) concerns the originality of the research and, to a lesser extent, its resonance. With regards to this issue, before interviewing the women, I discussed this matter with them by asking for their permission to discuss the findings for member-checking with them during the data collection. Subsequently, I used this option several times in situations where it was unclear what the women meant in their narratives (see also: Section: 5.2.5: Member-checking).

Next, regarding the resonance of the professional contact with the women, knowing the women prior to the study enabled me to develop the necessary early familiarity needed with them (Guba, 1981; Charmaz, 2006). Nevertheless, most of the women who became engaged in my project knew me as their therapist. In my work, creating familiarity, and thus, confidence, are the most valuable ingredients in our contact. However, it might be possible that owing to too

---

[24] Senior researcher = the supervision team. Members are: Prof. Dr K M Wright (PhD); Dr J E Duckworth (PhD); & P van der Graaff, medical doctor and psychiatrist.

[25] Chapter 4: The fundamental methodological steps of GT according to Charmaz, Section 4: 6.2.4, Data collection: memo writing.

close an involvement with the women, I might have ignored contradictory observations (Poelman, 2015). With this issue in mind, frequent debriefing with the supervisory team and the memo writing were the requirements that need to be taken into consideration with regards to the prevention of selection bias, which might otherwise occur in this project (see also the first bullet point of this section).

In conclusion, a collaboration of these techniques is needed to support the credibility of the research, and thus, for the handling of the bias phenomenon, see Section 5.2.5 for further explanation. Furthermore, using the techniques, brought insight into my personal predispositions regarding the topic of the research (Miles & Huberman, 1994, in Shenton, 2004). Due to the nature of a constructivist GT approach, my personal insights were a part of the process[26]. In addition, peer scrutiny was achieved during the research project, by performing several (poster) presentations and workshops, closely related to the research topic, to colleagues within the mental healthcare institution and in the specialist field of work. The external validity of the research was guaranteed by its transferability and by the appropriate use of the constructivist methodology, which contains an extensive description of the data collection and the analysis, along with the correct use of the saturation standard and the duration of the data collection (Guba, 1981). To guarantee the competence of the research, the protocol of the study and the study process were reported in detail to the supervisors. In this way, a subsequent researcher could replicate the study and achieve similar findings.

The following sections elaborate on the criteria which refer to the trustworthiness of this project (Charmaz, 2006).

5.2.1 Credibility

In terms of the insights regarding credibility (Charmaz, 2006), this study was based on the familiarity that was achieved through the contact with the women SE-AN sufferers. Furthermore, the interviews were conducted until the point of saturation in gaining sufficient in-

---

[26] Section 3.5.4 – Social constructivism according to Charmaz and Section 4.6.2.4 - Data collection: memos

depth data was reached. Therefore, the different techniques were used in a constant comparative process, in order to provide insights into the observations, which, in turn, supported the development of the categories, which were underpinned by the findings. Subsequently, the categories covered a wide range of empirical observations by building a strong and logical link between the gathered data and my analysis. The technique of memo writing, therefore, proved to be helpful and supportive. On this basis, it was claimed that the research provided sufficient evidence, and that I would hope to convince subsequent readers of the credibility of my findings and insights in this particular field (Charmaz, 2006: p 182).

5.2.2 Originality

In attempting to contribute to the originality of this study, carrying out the appropriate preparation and the presentation of the thesis itself was challenging. The starting point of this project was writing a clear research protocol by means of a brief overview of the existing knowledge on the topic. Furthermore, a clear description of the methodology and the methods of a constructivist approach, according to Charmaz (2006), was given. Next, the research question was discussed with my supervisory team, according to its relevance, originality and details, and the feedback was assimilated into the project. Furthermore, the project was prepared by setting up appropriate guiding questions (sensitizing concepts - see Section 5.2.1), and by providing a clear presentation of the data generation, the analysis and the presentation of both relevant and new additional findings which contributed to the existing knowledge on the phenomenon of SE-AN. Moreover, this project aimed to contribute to the social and theoretical significance in this field of research, whereby it attempted to contribute to the improvement of the daily practice within eating disorder services (Charmaz, 2006).

5.2.3 Resonance

Regarding the resonance of the study, this explicitly called for 'sound boarding[27]' with the women SE-AN sufferers, the supervisors and my colleagues (Charmaz, 2006). In order to keep in mind the relevance of the research question, the following points were considered:

- A developed Grounded Theory has to make sense to the people with whom it is shared. The people involved must be able to understand the circumstances of SE-AN, for example, the SE-AN sufferers themselves; their relatives; other important people in the lives of those with SE-AN; and also colleagues working within the SEDUs.

- Regarding the analysis, a Grounded Theory approach facilitates deeper insights for those who are interested in the topic of the research, for instance, other researchers. To create a useful resonance, frequent debriefing sessions with the supervisory team were conducted, followed by, summaries of the project's progress being presented at symposia, workshops, along with poster presentations. Furthermore, short overviews of the project and its findings were provided for the SEDU team and for specialist nurse colleagues.

The previous points also touched on the issue of 'usefulness' (Charmaz, 2006). By performing specific exercises, as described above, the project highlighted the significance of the findings. By frequent presentation of the interim findings and insights gained during the project, I attempted to stimulate others who are using or discussing new insights related to the topic of research. This is mostly seen on the ward where I work. Due to the nature of the topic, there is a continual generic process in relation to the women SE-AN sufferers and, by presenting

---

[27] Sound boarding: a person, group, experiment, etc. used to test a new idea, policy etc. For acceptance or applicability (https://www.collinsdictionary.com/dictionary/english/sounding-board)

and discussing the matter of the topic, I attempted to provide new insights for the women SE-AN sufferers, the healthcare workers and for the relatives of people suffering with SE-AN.

5.2.4 Concerning the trustworthiness of findings

Having worked through the early data sets, I turned back to the original recordings and field notes to verify my findings. In doing this, I ensured that the data was indexed and derived from the original interviews. Revisiting the original data is encouraged and, with this, initial codings can be defined and any resulting bias can be uncovered (Strauss & Corbin, 1990). Revisiting the data allowed new interpretations of the narratives of the women SE-AN sufferers, which might provide a broader view and could help to develop a deeper understanding of the data (Charmaz, 2006: p 70).

Furthermore, the women SE-AN sufferers acted as guides for this project (Chiovitti & Piran, 2003; Charmaz, 2006, 2010). Indeed, this scale of methods was essential for the credibility of the Grounded Theory approach, in order to maintain the rigour in this method (Coony, 2011).

5.2.5 Member-checking

In the study, I interviewed the women participants once. Whilst all the interviews were transcribed into written data, in terms of the credibility and conformability of the findings, I proposed new conversations with the women in terms of member-checking regarding the aim of confirmation of their narratives (Charmaz, 2006: p 111). Therefore, I gave the women the opportunity to meet me for a personal face-to-face conversation, or alternatively, contact by telephone, regarding the (in)accuracy of their narratives. By revisiting the data, the women could help to enlighten me as to any possible bias that may have occurred from the original Dutch narratives, which had been translated into English (Charmaz, 2006). Thus, confirmation of the accuracy of the narratives, and confirmation of the accuracy of the translations (Dutch into English) justifies revisiting for member-checking the women SE-AN sufferers in this project. Five of the women took advantage of this opportunity, and I turned back on the women participants. However, returning to all the women, as planned, was not possible because, sadly, one of the women passed away a few months after the initial interview, and two of the women did not respond to my call for a further conversation. In addition to this, a remarkable moment appeared; one SE-AN sufferers reread her interview, she turned back on me with a clear request for help. Her own words touched her personally, realizing that she really wanted to improve her situation as influenced by the Anorexia. I considered this incident as rather important and worthwhile mentioning since Glaser (2007: p 2) stated that *"all is data".*

5.2.6 Bias

Referring to previous sections (5.2 and 5.2.4), specifically in terms of confirmability, with regards to the *objectivity, does the researcher take into account her own biases?* (Guba, 1981: p 87). It was worthwhile explaining the phenomenon of 'bias' as a concept in itself.

A definition of 'bias' found on the internet:

> *"Bias is the disturbance in results of research by prejudice or manipulating in a certain direction"*
>
> (De Vries & Weijers, 2017)[28].

In evidence-based medicine, it is important to recognise that bias can occur, which might lead to the researcher making a misinformed interpretation of the data, and thus leading to a different outcome. Burger & Hofman (2005, in van de Meer & Stehouwer, 2007) characterise three main types of bias, which are as follows:

1. Selection bias - the sample used in the study is not representative for the population.
2. Information bias - the information of participants needs to be complete and qualitative in good condition. Information bias is usually a topic in randomised controlled trails, a form of research, classified as most valuable.
3. Confounding bias - a distortion by a third factor associated with the determinant and the outcome.

In the 1960s, quantitative researchers rejected qualitative studies, labelling them as impressionistic, anecdotal, unsystematic, and thus, biased (Charmaz, 2006). Objectivist

---

[28] De Vries & Weijers (2017). http://www.cmotions.nl/5-typen-bias-data-analytics/.

grounded theorists attempt to create a tendency in GT to reside in positivist research, whereby the data already exists in the world, and the grounded theorist discovers it (Corbin & Strauss, 1990; Glaser, 1978; Glaser & Strauss, 1967 in Charmaz, 2006). Nevertheless, regarding the above points, handling bias in qualitative research is challenging, and there is continual debate regarding the credibility of qualitative research and how to interpret qualitative findings in daily practice. One example of this debate is found in the work of Willems & van Zwieten (2004), which referred to the credibility of qualitative research connected to the daily practice of a general practitioner (GP). Willems & van Zwieten (2004) explicitly underpinned the possibility of using qualitative data findings, if a patient does not respond to the standards based on the outcomes of the quantitative research. For them, qualitative findings are in addition to quantitative data (Willems & van Zwieten, 2004) and they concluded that qualitative findings are valuable in offering a GP a better understanding of the patient's situation and perspective, and further, Willems & van Zwieten (2004) proposed that qualitative results offer a good reason to decline the standard evidence based on quantitative standards. (Willems & van Zwieten, 2004).

The nature of this project is the study of the effects of severe and enduring Anorexia on people. For example, in terms of the selection bias, whatever the findings, these cannot be treated as representative for the population as a whole. The findings of a qualitative study strongly supported the view that each SE-AN patient should be treated as an individual. For this reason, and with regards to my personal interest, which I incorporated into my work, I have chosen to study my own patients with whom I am familiar. However, this gave me the important task of challenging myself as to how I am going to prevent bias. After Charmaz (2006), I quoted Glaser (2007), who suggests that there is no such thing as bias in qualitative research. Indeed, it was Glaser who stated that "*all is data*", but would not be drawn into explaining what data actually is. *"Data is not truth and is not reality"* (Glaser, 2007: p 2). As a result, my supervisor referred me to an on-going debate[29] relating to this topic, which, in turn, led me to the work of Singh & Estefan (2018), who represented the stance of Charmaz (2006), whereby Charmaz advocated including the researcher's influences and values. In her opinion, such data are worthy. With this in mind, each course of action carries its own meaning. In the end, meaning will emerge, directed by patterns in the constant comparative method (Charmaz, 2006; Glaser, 2007).

5.3 Ethical considerations

To ensure compliance with ethical requirements, permission to perform this study was requested of and granted for a Professional Doctorate at the University of Central Lancashire, Preston (UCLan) (Appendices: 2 - 2.1). Then, approval was also sought for the registration of this study by a Dutch medical ethical committee (METC), attached to Emergis, the METC of the Erasmus Medical Centre, Rotterdam (Appendices: 3 - 3.1 - 3.2 - 3.3). As described in the previous chapters of this thesis, it is acknowledged personally, practically and scientifically that the participants of this research, the women with SE-AN, are a vulnerable group.

This section describes how I have applied the ethical considerations and the means by which I have managed the perceived vulnerability of the research population in this study, as well as describing the informed consent process, how confidentiality and anonymity are dealt with, and also the issue of funding. In order to address the issue of vulnerability in the context of people with SE-AN, a representative definition of 'vulnerability' is given. Gobbens et al. (2010) attempted to develop a holistic framework and defined frailty in older people. However, despite the difference in age, comparing older people to people with SE-AN does demonstrate an overlap of multiple problems in both groups. Gobbens et al. (2010) defined this concept of 'vulnerability' as:

---

[29] https://www.researchgate.net/post/What_are_and_how_are_Charmazs_data_analysis_with_constructivist_grounded_theory_different_from_Glaser_and_Strauss_and_Corbin

> *"A dynamic situation in which an individual interacts and deficits in one or more areas of human functioning (physical, psychological, social), which under the influence of a variety of variables is caused and that the likelihood of the occurrence of undesirable outcomes increases."*
>
> (Gobbens et al., 2010: p 26).

Hence, I was able to conclude that, although the population is often physically frail, they were very able to consent to the research and to being interviewed. In reality, it is quite usual for women with AN to be rather robust in their opinions and willing to share these with their healthcare workers and any researchers.

5.3.1 Ethical Framework

In this study, ethics were defined in the following way: *"Ethics is a systematic study of the moral, the moral is the sum of values and norms"* (Vellinga & Van Melle, 2016: p 209). Traditionally, ethics are related to the applicable rules of a particular community, and to the personal balance as to how those rules are handled (Ten Have et al., 2009). In medical ethics, the source is found in the moral qualities of Hippocrates (460–370 BC). The values of 'beneficence' and 'non-maleficence' (a further explanation of these values is given in Section 5.3.3) are central to the oath of Hippocrates (Vellinga & Van Melle, 2016). With regards to the focus on health and the quality of life of people with a severe psychiatric disorder, this project chose to frame the ethical considerations according to the Hippocratic Ethical Principles of Beauchamp & Childress (2012), who examined bio-medical ethics. Although Beauchamp & Childress (2012) did not claim that this is the only way to guarantee ethical integrity in research, their ethical principles would provide a theoretical frame in the search for evidence-based practice (EBP) for people with SE-AN. EBP is the conscientious, explicit, and judicious use of the best available evidence when making a choice for the treatment of a patient (Sackett et al., 1996). There are many definitions of EBP. Most definitions include the following three aspects that are used in making clinical decisions (Kuiper et al., 2008) and are as follows:

- the current best available evidence;
- the knowledge and experience of the (para-) medic; and

- the preferences of the individual patient

To increase knowledge of the SE-AN phenomenon, empirical research has to be conducted which is based on the principles of EBP, and has explicitly taken account of the ethical principles involved. These ethical principles are based on the concepts of 'autonomy', 'beneficence', 'non-maleficence' and 'justice (Beauchamp & Childress, 2012). Although these principles might appear to conflict with each other, moral dilemmas might be discussed on the basis of these values, where, at least one particular value might prevail (Vellinga & Van Melle, 2016).

5.3.2 Autonomy

Autonomy is the value of defining patients' own choices and is sometimes referred to as the right to be self-determining. In this project, the women were personally invited to attend an interview with me, and also via an information letter (Appendix 4), which was given to them personally at the same time. This information letter contained the explanation of the aim and objectives, and the method of the research, and furthermore, it explained the possible outcomes if the women decided to participate. In this letter, the women were encouraged to discuss their decision as to whether they participated with me or not and also to discuss their decision with their families and friends. In addition, they were also provided with my work contact details, in case they had any further questions or concerns about the project or their involvement. They were assured that there were no consequences if they refused to participate. Similarly, if any of the women did decide to join in this study, an informed consent form had to be signed, which contained all the conditions for the participant. However, all the women were informed that they could withdraw from this study at any time, although the data already collected up to that point would still be included in the research, if the women decided not to participate any further. Once the interview had been carried out, the women were invited to visit me again in the role of researcher, to discuss the narrative in general in order to strengthen the credibility and the conformability (Charmaz, 2006). (See also, Section 5.2.4, concerning the trustworthiness of the findings.

5.3.3 Non-maleficence and beneficence

In the medical tradition, the value of 'non-maleficence' is more important than the value of 'beneficence' (Vellinga & Van Melle, 2016). In order to give a better understanding of these principles, a brief explanation of 'beneficence' and 'non - maleficence', as formulated by Pantilat (2008)[30] is given.

" Beneficence is action that is done for the benefit of others. Beneficent actions can be taken to help prevent or remove harms or to simply improve the situation of others."

(Pantilat, 2008
http://missinglink.ucsf.edu/lm/ethics/content%20pages/fast_fact_bene_nonmal.htm).

Hence, Pantilat (2008) describes the value of 'non - maleficence' as follows:

" Non-maleficence means to "do no harm" "

(Pantilat, 2008
http://missinglink.ucsf.edu/lm/ethics/content%20pages/fast_fact_bene_nonmal.htm).

In the concept of non-maleficence, there are multiple forms to distinguish. These are physical and psychological damage, harming the patients' personal interests, harming the moral integrity, and inflicting injustice on someone. In this study, there was a slight risk that the interview could cause some distress and, therefore, be seen as 'harmful' to the women. I was aware of the fact that both values of beneficence and non-maleficence can conflict with each other, and thus, in this study, I have chosen to give specific attention and care to the women with SE-AN, who were invited to take part in a personal interview about how they experience their quality of life. I am an experienced nurse and therapist and I am highly skilled in managing emotional and sensitive conversations with people, and therefore, I had no concerns that any harm will come about as a consequence of taking part in this study. Despite this, I still needed

---

[30] http://missinglink.ucsf.edu/lm/ethics/content%20pages/fast_fact_bene_nonmal.htm

to acknowledge any potential risks which would be against the principle of non-maleficence (Beauchamp & Childress, 2012; Vellinga & Van Melle, 2016). Firstly, the length of the interview would not exceed 60 minutes. Due to the physical and psychological condition of the women, a longer duration for the interview might be exhausting. Secondly, the questions posed during the interview might be difficult or painful, and the women could get upset due to the personal and sensitive nature of the questions. Thirdly, there was also the possibility that the interviews might take place in the own environment of the participant. Visiting a vulnerable person in her own environment could appear threatening for them. For these reasons, I have made some adjustments, which are as follows:

- Before the start of the interview, I explain these possible risks to the participant, both verbally and in written format, by means of the informed consent form (Appendix 5).

- The participant will be asked if she prefers to perform the interview via computer, telephone or face to face. The advantages and disadvantages of the various interview methods will be considered with the participant to allow them the possibility of making an informed choice.

- In this project, I am acting as a nurse specialist, in order to preserve the boundaries in this project as a researcher, during the interviews, no therapeutic support is given, even if it is needed. I am, as a researcher, under an obligation to inform the SEDU if an emergency arises (Appendix 6 - Declaration of patient insurance participating in research [Dutch version]). It is being considered as to whether to offer the possibility of specialised psychological help from a trained professional, if needed, after the interview. This decision will be discussed with the participant in terms of respecting their autonomy (Beauchamp & Childress, 2012; Vellinga & Van Melle, 2016) and with the supervisors. Hence, I am aware of the fact that any given information is not confidential anymore, but this decision respects the value of beneficence (Beauchamp & Childress, 2012; Vellinga & Van Melle, 2016).

Another, although unlikely, possibility could be the potential impact of the study upon the multidisciplinary team. In this study, the team members were informed about the project by means of a poster presentation. Although team members were not involved in this particular research, it might be possible that team members experienced some effect from the project in their work with their patients. It was possible that the women SE-AN sufferers might prioritise who they speak to, they might make comments referring to the different conversations that they have had with me in the role of researcher, or they might chose to make a complaint, or express their criticism about another member of the care team. If this occurred, I would be obliged to direct the woman to the complaints procedure. This decision was based on the principles of non-maleficence. Thus, for this reason, it was especially relevant to keep my colleagues well-informed.

5.3.4 Justice

The ethical Principle of Justice would be considered in this research due to the method of sampling and the recruitment of the women SE-AN sufferers. The women were selected from the patient files of the SEDU at Emergis (a mental health institution in the Netherlands), to which I already had access in respect of my employment. Another consideration of the Justice Principles was the fact of potential expected bias that scholars had with regards to this group, since people with SE-AN were often excluded from empirical research (Noordenbos et al., 2000). Thus, research into the topic is justified, as it contributed to the understanding of the phenomenon, in terms of the quality of life of people living with the diagnosis of severe and enduring Anorexia Nervosa. Conducting such research helped to give them a voice, and therefore, carrying out this project might even strengthen the position of this patient group.

5.3.5 Anonymity

All women gave their permission for the use of their personal data in scientific research by signing an informed consent form, which contained their personal information. The informed consent forms are kept in my personal computer, which is password protected. Interviews with the women were recorded digitally, and verbatim transcripts were written from these recordings. All the personal data files, the interviews and the notes/memos were made anonymous by giving the women a pseudonym, and also by striking through the personal data on the copies of the files. The document files were then saved on my personal computer and stored in the MAXQDA (Version 2018) program. By removing all the personal data from the transcripts of the interviews, the women could not be identified in any publications.

5.3.6 Sponsorship/fundings

During this study, I collected, analysed data and constructed a theory on at least one day per week, but mostly this was carried out on three days a week during the course of three years. No funding or payment for the additional study work was secured. I funded the course myself and conducted the research in my own time.

5.4 Summary

In this chapter, I have given attention to the trustworthiness and the ethical underpinnings of this study. Furthermore, I have elucidated on the credibility in general, as used in qualitative research and, more specifically, I defined and underpinned the concepts of credibility, transferability, dependability and conformability according to Guba (1981) to strengthen the findings of this study. In turn, this made this project more valuable, more transparent, and the findings more robust. The detailed concepts were closely related to Charmaz' (2006) method, and the issues relating to bias as seen in qualitative research was examined. Moreover, I also scrutinized the questions relating to credibility, originality, resonance and usefulness in detail according to Charmaz (2006), and explained the trustworthiness of the findings during the data analysis process. Finally, I elaborated on the ethical framework within the following topics: the ethical considerations, autonomy, non-maleficence and beneficence, justice, anonymity and, finally, the funding/sponsorship of the project. In the next chapter, I expand upon the methods of analysis used in this study.

Chapter 6 The analysis of the data

6.1 Introduction

In this chapter, I identify and present the women participants and their SE-AN experiences, which were conveyed during the interview process. The data reveals their social processes, as is required in GT. Within the method of analysis, I provide a level of transparency, which reinforces the credibility of the research and maintains the rigour of GT (Chiovitti & Piran, 2003; Charmaz, 2006; Charmaz, 2008; Coony, 2011). In this phase of the study, rigour is maintained and credibility is increased by the use of the women's actual words, by keeping a personal journal and by writing the memos (see also Section: 4.6.2.4 and Section: 6.2 [31]).

In addition, I present the data analysis, guided by Charmaz' (2006, 2008) method. At the start, the initial codes were used to make the primary minor theoretical findings. During this process, I merged three techniques, which were: (i) line-by-line coding, diagramming the early findings; (ii) utilizing a mind map; and (iii) writing the memos of each narrative. This process was followed by the next step in the analysis, which was the process of focused coding, whereby all three of the supervisors participated in simultaneous coding, which leads to a firm and rigorous approach, and which helps avoid bias in the research. This also brings the analysis towards the final theoretical categories that will be used. I then describe the process of theoretical coding, wherein I merge the axial coding (see also Section: 4.6.4) in respect of the explanation of the relationships between the categories. In other words, it gives meaning to the social actions the women experience. Next, I describe the theoretical adequacy and give an explanation of the literature review approach, as used in a constructivist theory (Charmaz, 2006), typically using a flexible approach. The section below provides an introduction to the women participants.

---

[31] Section 4.6.2.4: Data collection: memos and Section 6.2: Introducing the participants

6.2 Introducing the participants

Regarding the epistemological stance of Constructivism, according to Hayes & Oppenheim (1997) and Pigeon & Henwood (1997, in Mills et al., 2006), Constructivism includes the subjective interrelationship and the co-construction of meaning between the researcher and the participant. As seen from the ontological point of view, constructivists negate the existence of an objective reality, which proposes a relativist ontological position. Thus, a constructivist Grounded Theory pays attention to the representation of the people participating in the study. Hence, it is important to present, not only the data, but also the participants, since, unlike in other methodologies, I do not simply reflect on neutral reports, but I intend to present the unique experience of each of the women SE-AN sufferers and her understanding of the topic being researched (Charmaz, 2006). Furthermore, to conform to the constructivist theory, I will take a careful account of the meanings the women attribute to their interpretations of reality. Charmaz (2000, in Mills et al., 2006: p 153) argues that GT researchers should maintain a certain distance from their study subjects as, otherwise, this might negatively interfere with the development of the 'co-construction of experiences' and the meanings in the Grounded Theory (Mills et al., 2006), which I consider as a valuable warning concerning my involvement in the account of the preparation of a co-construction. As Charmaz stated, *"[d]ata is not a window of reality, data is temporal, cultural and influenced by structural contexts"* (2000: p 524).

Hence, I provided a short and cohesive summary of each participant. The following paragraphs contain a brief and personal description of the women and their experiences within the interviews. In order to guard their confidentially, I chose to give each participant a pseudonym. The capital 'I', which is used in the excerpts of the narratives, stands for 'interviewer', in other words, myself. In the next section (6.3: Table of participants), I processed the demographic details of the women participants. To enrich each description, I provided a brief extract from their interviews, in order to create some distinction and to reveal some elements of their personality, as well as their position within the study.

6.2.1 “Amy”

At the time of the interview, I acknowledged my relationship with Amy, as she was one of my patients. During her life, Amy had suffered from different types of eating disorders. Eleven years ago, her illness demonstrated the characteristic features of Bulimia Nervosa, but a few years later, her eating disorder had modified into Anorexia Nervosa, but with purging characteristics. Amy felt like the eating disorder executed complete power, both over her and over her family. Amy explained to me that her family is very important to her. During the interview, although Amy was very keen to explain her views on her former treatments, her thoughts on failed treatment experiences, her homesickness, and the fact that she continually missed her relatives, made her very emotional. An example of Amy being a captive of her Anorexia is shown in the following quote:

> *“It’s like I’m in a theatre, on stage, you know the scaffolding all the way up, above the stage? Where the lights are? I have the feeling that the eating disorder is all the way there and determines what I have to do on stage. And, if I remember it well, yes, my family is the public, they are watching the tragedy of my life”.*
>
> (Amy: L110).

6.2.2 “Sarah”

During the interview, Sarah benefitted from the in-patient setting, though she did not belong to my patient caseload. In addition to the suffering from the eating disorder, Sarah deals with continual physical problems, as a result of a severe sports accident in her youth. Sarah strongly promotes being seen as a complete person and she definitely does not see herself as the *“girl with the eating disorder only”*. Despite the fact that the eating disorder always demands her attention, Sarah attempts to live as normal a life as possible. She has a relationship and she is financially independent. Armed with a strong sense of humour, she laughed out loud at herself, while explaining her odd anorexic behaviour. During the interview, Sarah explained how she recently found a tenuous balance concerning contact with her family. The next quotation illustrates her view on this delicate matter:

> *"About my behaviour, I noticed the sadness of my parents, they were broken. I've made the decision; I will work it out by myself, so I can protect them against the pain of having an ill daughter. By doing this, they succeed in getting the control back".*
>
> (Sarah: L49).

6.2.3 "Mabel"

Mabel is a quiet, very modest woman in her forties. Mabel appeared to me to be a very fragile person, as her Anorexia has left its physical and psychological marks, and she is damaged by the burden of a severe complex psycho - trauma. The interview is characterised by guilt, blame and the constant urge to defend herself to other people. Her life is determined by eating disorder 'rules' and the urge to engage in physical exercises. Mabel is married, and she developed Anorexia during her marriage at the age of 28, which is labeled as a late-onset Anorexia Nervosa. Mabel lives a withdrawn life in a small town and has hardly any social contacts. During the interview, she benefitted from nurse support by visiting the outpatient setting of the service. Her quotation underpins her lack of social contacts:

> *"I feel the pressure, the load on my shoulders of what people think of me. Yes. That's very important. This is one of the reasons why I never go out".*
>
> (Mabel: L124)

6.2.4 "Fiona"

During the interview, Fiona received in-patient treatment. She was especially prepared to tell me about her experiences and also her ideas for treating people with Anorexia Nervosa. Before her current treatment, it took me some time to build up Fiona's confidence, but after a while, I managed to win her trust. In relation to this matter, Fiona told me that her distrust of people is second nature to her. She connects her current behaviour to her childhood, when, for years she was neglected. Nowadays, Fiona has developed into a woman who keeps an appropriate distance from others, but is now a more spontaneous and amiable person in company than previously. To reach this level, Fiona has received help from her aid dog, who is always beside her and who supports her in getting connected with other people, even during the in-patient treatment and during the interview. Fiona often allowed me to look into her emotional life; regarding the conviction she has, keeping secrets from others, which she did, will not bring her any relief. Fiona has struggled with Anorexia for more than twenty years. In most of our conversations, Fiona enjoys a good laugh, however, for the interview, she was well prepared and serious. Fiona strongly promotes the idea that she must gain weight in order to survive. For her, that is the way to improve her quality of life. The next quote describes her vision on weight gain:

> *"I have known episodes at the beginning of my eating disorder. I had a depression. Later on, it was not that important anymore. But then, I was partly recovered, I had a normal weight in those days, the depression was gone. People described me as a joyful person then, I radiated happiness. Thus, that situation I do connect it to a healthy weight. They say: a healthy psyche and a healthy body are going together. I think that is true. Maybe not for everyone, maybe there are people with an eating disorder who stay depressive while they having a normal weight but I think that a better weight is less illness, you have more power so you can fight harder against the disease".*
>
> (Fiona: L74)

6.2.5 "Sandy"

Interviewing Sandy was an exciting experience for me. Sandy, a woman in her early forties, was a trained and an experienced family therapist. At the time of the interview, she was not able to visit the service but she agreed to conduct the interview by means of a tablet device, so, we were able to see and speak with each other using Skype. I was not sure if the equipment would work and if the internet connection was stable enough, and these circumstances made me nervous, especially as it was the first interview of my project. However, it worked out very well. We were both at our homes for the interview, and Sandy was able to see my dog in the background and so, during the interview, dogs were often spoken about. At the start of the interview, Sandy took the lead in our conversation. She talked about her dog and how important he was in her life. We definitely shared a love of our dogs. The history of her illness impressed me very much, even though I had known her for more than ten years. The interview revealed new information, which I considered as the more subtle, but impressive, experiences in her struggle with her Anorexia. Sandy had suffered from Anorexia for more than twenty years. She felt it had taken over her life. The next quote demonstrates the lead that Sandy took in the interview, especially concerning the dog in our conversation:

> *(Sandy asked me):"Do you have the idea that you neglect the dog?*
> *I: I always think I neglect him and I guess that he thinks that I always neglect him.*
> *S: Yeah, look at him looking droopy and I feel myself... I notice myself feeling very unsure so I am going to follow a dog training (Sandy owns a dog), an individual training to learn some more, more self-esteem. I am very consequent in my behaviour in approaching the dog, but, naturally, like the previous week, than my eating disorder troubles me the whole day".*
>
> (Sandy: L50-52)

6.2.6 "Sophie"

I was looking forward to interviewing Sophie. Despite the fact that she visits the outpatient service, I have not seen her for months, but she expressed enthusiasm when I asked her to participate in this study. Sophie is familiar with keeping a distance. In the past, we agreed that Sophie could use the service if necessary, and I am Sophie's therapist. I have known Sophie for at least eight years, and I have experienced her situation at several different stages. When we first met, Sophie was enslaved by her Anorexia. More recently, Sophie has reported more balance in her life, even though her Anorexia still has power over her. I know Sophie as an intelligent woman, however, through her condition, she is not able to work. Nowadays, Sophie has succeeded in having a relationship, which was a goal she was dedicated to achieving, and I am happy for her. Regarding our interview, and as usual, Sophie appeared punctually and, at the start of the interview, she assured me that she is really committed to contributing to my project. The following quote from the interview illustrates the lived influences of the Anorexia in Sophie's life:

> *"I think that I've lost a part of my identity as a person, as Sophie, the eating disorder took a part of my identity, I do things I do want to do but I have to. I make choices but they aren't mine. It's like something has stolen from me, it feels like they took it away from me".*
>
> (Sophie: L31)

6.2.7 "Mariah"

I have known Mariah for three and a half years. At the time of the interview, she was a patient within the in-patient service, which is her third time on the ward. It is her frailty in appearance that made me curious about her perception of life, and how she experiences her life as an SE-AN patient. I am her therapist, and at the beginning, our contact was slightly laborious, but our continued contact strengthened the confidence between us. Mariah has received care from the service for at least twenty years. During her trajectory, different health care workers were involved in her progress. Mostly, the care was classified as curative to support Mariah in the social domains of work, leisure time, and in terms of being financially independent. Her confidence in healthcare workers was, and still is, frail, and is influenced by the negative impact of a major event she experienced with regards to her care. Twenty years ago, the multidisciplinary team decided to nurse Mariah separately, which meant a transfer into an isolation room because of her loss of reality, which had been caused by the impact of the eating disorder. Since I am now her therapist, my goal has been to support her in the search for improving her quality of life. However, I am affected by the impact the eating disorder has had on the life of this very sympathetic female. The following quotes from Mariah reveal the impact of her thoughts on how she experiences her suffering because of Anorexia Nervosa:

> *"I feel myself so very fat, I see it in the mirror and I see it in windows when I walk on by, I feel myself so, so very fat, so fat.*
> *I: Do you have to look at yourself constantly, in windows, in mirrors?*
> *M: Oh yeah, I notice I have to stand on a chair to watch in mirrors, and I see it everywhere that I am so very fat. I can't see it that I am...*
> *I: That you are thin?*
> *M: Exactly, not at all, I can't see it".*
>
> (Mariah: L126-130)

6.2.8 "Violet"

At the time of the interview, Violet had been using the in-patient service for six months. Although she has suffered from Anorexia for at least seven years, nevertheless, Violet is one of my youngest patients, aged 20. The moment Violet became ill, she went through several in-patient treatments on three different SEDU's in the Netherlands, and on each occasion, she restored her weight. Despite this fact, as soon as Violet was discharged from the in-patient setting, she relapsed, and her core eating disorder pathology regains control, which results in her eating less, avoiding richer meals, and engaging in intensive exercise.

Violet is a sensitive person. She is always very friendly, has a sense of humour, and she has pleasant words for everyone. At the same time, this behaviour seems to work as a cover-up for the emotions she experiences. My contact with her and her family has been intensified since her stay in the unit, as a result of the very severe physical condition Violet experienced. Hence, Violet experiences trouble in restoring her weight, In the therapeutic sessions with Violet, I approach her as a young adult, who is learning to stand up for her own personal needs, although I do have the impression that the eating disorder has greatly influenced her personal development into adulthood, which is illustrated in the quote below:

> *"I feel myself 18.*
> *I: And how does it feel?*
> *V: I'm not really an adult".*
>
> (Violet: L234-236)

6.3 The demographics of the participants

Regarding the relevance of the women's details with regards to the stance of the constructivist approach (Charmaz, 2000, 2006; Mills, 2006) (see also Chapter 3, Section: 3.5.4[32]), I have chosen to incorporate the personal characteristics of the women in order to gain a better understanding of the constructs seen in the background and the personality characteristics of the participants, whilst being mindful of confidentiality issues (see Chapter 5, Trustworthiness

---

[32] Section 3.5.4: Social constructivism according to Charmaz

of the GT; Section 5.3, Ethical considerations). Table 6.1 below gives an overview of the demographics of the women participants.

Table 2: Demographics of the participants

Pseudonym	**Age**	**Diagnosis**	**Age of onset**	**Psychiatric Comorbidity**	**Years of treatment**	**Employment**
Sophie	35	Anorexia nervosa Restricting type	16	Obsessive Compulsive personality disorder	> 15	Former employer in the tourist sector
Mabel	43	Anorexia nervosa Restricting type	28	Dependent personality disorder	> 6	Former secretary
Sarah	28	Anorexia nervosa Purging type	13	Unspecified personality disorder	> 7	Speech therapist
Fiona	35	Anorexia nervosa Restricting type	15	Autism spectrum disorder	> 17	None
Amy	25	Anorexia nervosa Purging type	14	Borderline personality disorder	> 7	Student
Sandy *(Died in July 2017)*	43	Anorexia nervosa Purging type	17	Unspecified personality disorder	> 7	Former family therapist
Mariah	40	Anorexia nervosa Restricting type	20	Social phobia	>20	Administrative employee
Violet	20	Anorexia nervosa Restricting type	13	Avoiding personality disorder	>7	None

6.4 The process of initial coding

The first phase of the data analysis process was the initial coding of the data, and the interview transcripts (Charmaz, 2006; Charmaz, 2008: pp 163-165), which were written verbatim, and directly translated into English to enable scrutiny of these by my English-speaking supervisors (Strauss, 1987, in Charmaz, 2006) (see Section 5.3.2.1: Data collection: initial coding). I have used the technique of line-by-line coding, as Charmaz (2008: p 164) argues that line-by-line coding forces the researcher to interact with the data. The technique supported me in interpreting the data-making comparisons (of the data set itself and/or with other data sets). Whilst reading the text of six of the transcripts (for Mabel, Sarah, Fiona, Amy, Sophie and Sandy), I highlighted extracts of text and labelled it in a descriptive way, which allowed me to stay in touch with the events in the texts, and to preserve the data in such a way as to allow fast conclusions and interpretations (Charmaz, 2006: p 48; Charmaz, 2008: p 164). During the initial coding process, I used ‘gerunds’, which are noun forms created from verbs (Charmaz, 2008: p 164), for example, the noun (gerund) ‘judging’ from the verb ‘judge’. This was done to determine the action in certain extracts of text. An example of an initial line-by-line code is given below in Figure 6.1:

Initial code name: Judging by others for ‘being weak’
“An example, we go out for dinner with a group of friends, “ let’s not invite Sarah because she always says no”. But I think, who knows, maybe I’m having a good day and I like to go out with them. But they don’t even ask that kind of things anymore, That’s how people treat me in the outside world”. (Sarah: L37)

Figure 6.1: Example of initial coding

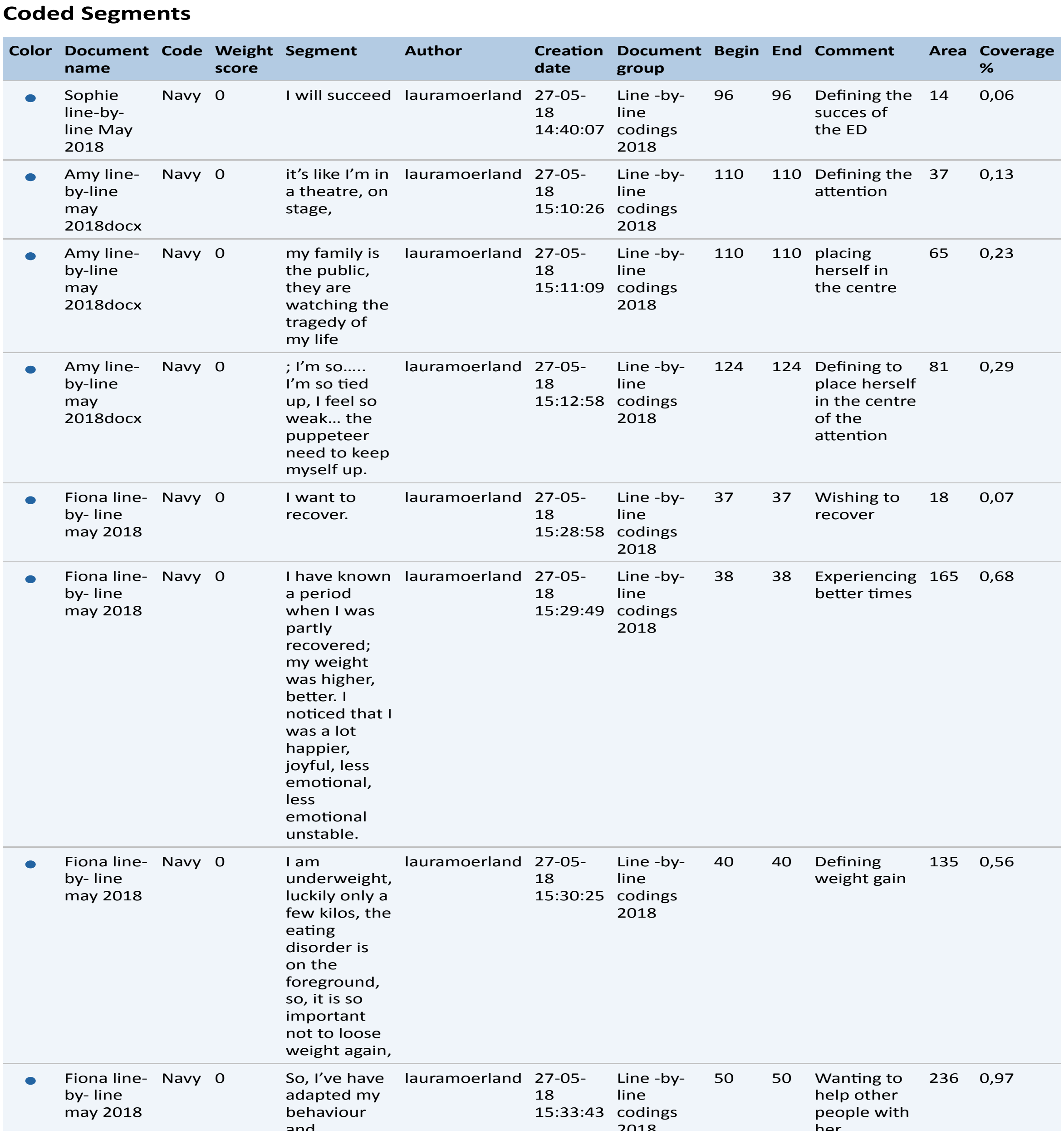
I have read the data sets repeatedly, and have highlighted the frequently-used words or phrases that appeared to be meaningful to those with SE-AN, that is, the in-vivo codes. In-vivo codes are the direct statements of the women (Charmaz, 2008: p 164), and these codes may be helpful in processing the theoretical insights of the topic of research (Strauss, 1987). An example of an ‘in-vivo’ code used in the data analysis is given below:

> *“I interpret my development as fat”.*
>
> (Amy: L46)

Regarding the issue of the management of large amounts of data, I chose to mark chunks of texts using a simple colour system to prepare the early categories (see Figure 6.2). Marking texts in this way appeared to be a helpful tool in order to get an easier overview, as it supported the comparison of the different categories in the data revealed earlier. Furthermore, the findings were thoroughly discussed with the supervisory team as recommended in Charmaz (2006) and Chiovitti & Piran (2003). The process of line-by-line coding and comparing the data split the narratives into broader categories, which revealed the following early groups:

- Green = Influences of psychological and physical functioning
- Light blue = Social functioning
- Yellow = Contacts with caregivers
- Orange = Relatives
- Navy = Positive influences and decrease of ED symptoms
- Red = Eating rules

The illustration (Figure 6.2) below represents a fragmental insight into the colour system that has been used, utilizing the MAXQDA program, and referring to the positive influences and the decrease in ED symptoms.



Coded Segments

Color	Document name	Code	Weight score	Segment	Author	Creation date	Document group	Begin	End	Comment	Area	Coverage %
●	Sophie line-by-line May 2018	Navy	0	I will succeed	lauramoerland	27-05-18 14:40:07	Line -by-line codings 2018	96	96	Defining the succes of the ED	14	0,06
●	Amy line-by-line may 2018docx	Navy	0	it’s like I’m in a theatre, on stage,	lauramoerland	27-05-18 15:10:26	Line -by-line codings 2018	110	110	Defining the attention	37	0,13
●	Amy line-by-line may 2018docx	Navy	0	my family is the public, they are watching the tragedy of my life	lauramoerland	27-05-18 15:11:09	Line -by-line codings 2018	110	110	placing herself in the centre	65	0,23
●	Amy line-by-line may 2018docx	Navy	0	; I’m so….. I’m so tied up, I feel so weak… the puppeteer need to keep myself up.	lauramoerland	27-05-18 15:12:58	Line -by-line codings 2018	124	124	Defining to place herself in the centre of the attention	81	0,29
●	Fiona line-by- line may 2018	Navy	0	I want to recover.	lauramoerland	27-05-18 15:28:58	Line -by-line codings 2018	37	37	Wishing to recover	18	0,07
●	Fiona line-by- line may 2018	Navy	0	I have known a period when I was partly recovered; my weight was higher, better. I noticed that I was a lot happier, joyful, less emotional, less emotional unstable.	lauramoerland	27-05-18 15:29:49	Line -by-line codings 2018	38	38	Experiencing better times	165	0,68
●	Fiona line-by- line may 2018	Navy	0	I am underweight, luckily only a few kilos, the eating disorder is on the foreground, so, it is so important not to loose weight again,	lauramoerland	27-05-18 15:30:25	Line -by-line codings 2018	40	40	Defining weight gain	135	0,56
●	Fiona line-by- line may 2018	Navy	0	So, I’ve have adapted my behaviour and	lauramoerland	27-05-18 15:33:43	Line -by-line codings 2018	50	50	Wanting to help other people with her	236	0,97

Figure 6.2: Example of forming early codes by using colours (navy)

Regarding the figure above, I started with a rough coding system, guided by colours. However, later in this project, I decided to use the colour system in the mind map (Simple Mind Lite) only, despite the fewer opportunities that MAXQDA offered in terms of the segments tool, as used in the illustration above. The MAXQDA program did not challenge me to merge the several colour segments, and thus the appeared data. Nevertheless, working towards the analysis, the increasing number of insights of early categories appeared when they were re-organised in a diagram utilizing Simple Mind Lite[33] (Mac version) (See also Figure 6.3: Diagramming initial codings). With this technique, I developed a better understanding of the conceptual analysis process by having an actual overview of the findings. Thus, the visualisation of colours, and thus, the early-formed categories, appeared to be especially helpful in the discovery of the theoretical categories.

---

[33] Simple Mind Lite is a free software program, compatible with Mac.

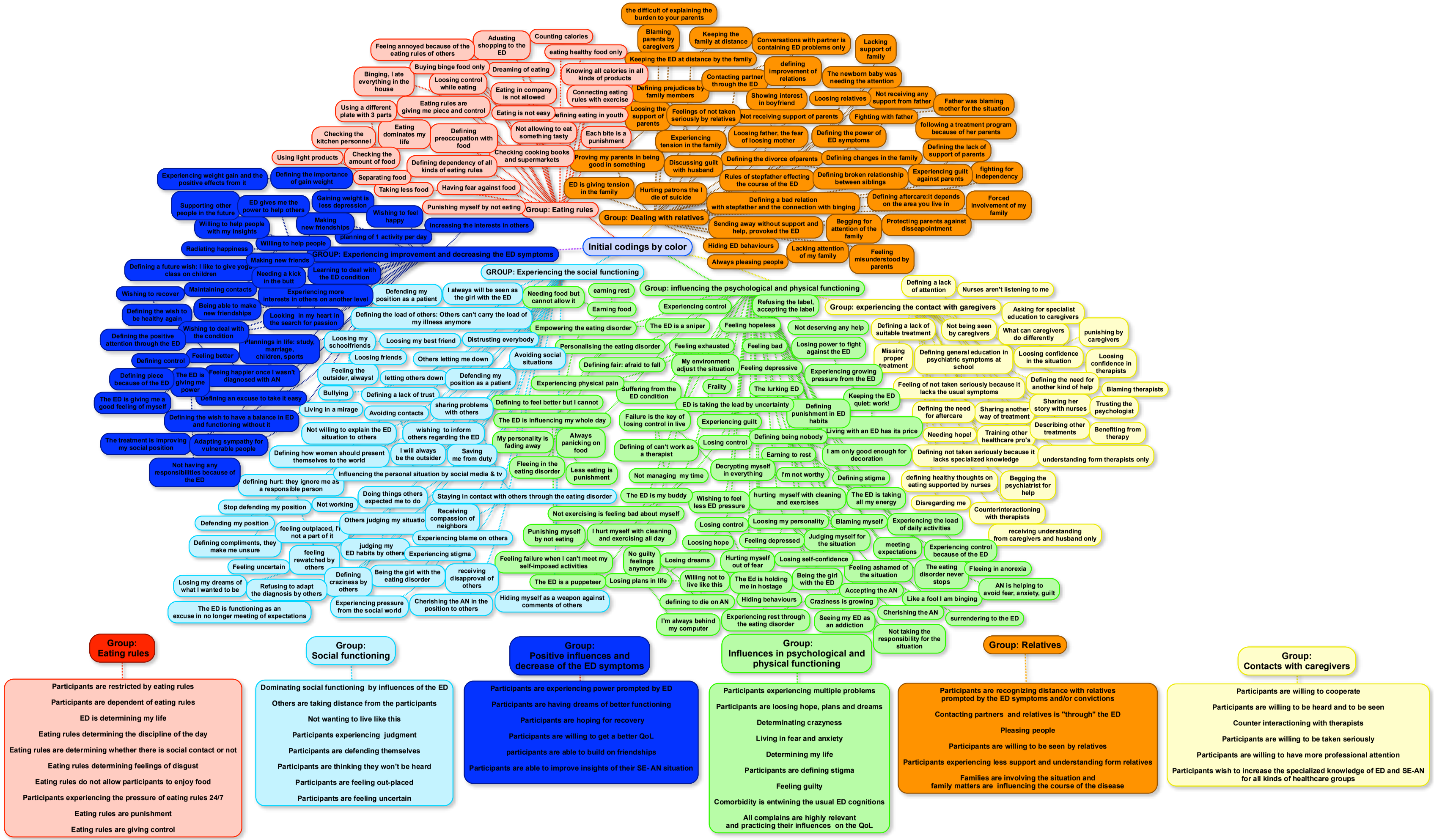


Figure 6.3: Diagramming initial codings

6.4.1 Using memos

Regarding my thinking process during the initial coding, I decided to write a memo for each data set, (see Section 4.4.2.1: Data collection: initial coding). Writing memos during the analysis appeared to be useful in developing a broader overview of the personal data, and this supported me in the separation of the early codes with regards to the findings. Furthermore, this enabled me to place the codings in their context, which provided me with new insights into the narratives, and with this, came the possibility of looking beneath the surface of the narratives. In addition, this supported me in being able to discover more empirical evidence. In the memos, I assimilated the main questions that Glaser had formulated and had proposed using during the analysing process (Glaser, 1978 in Charmaz, 2006) while writing the memos, which brought me a better and more in-depth understanding of what the actual data was really about. See, for example, Mabel's memo (Memo 3) below. Furthermore, writing the memos challenged my thoughts about the experience of the interview at a point very close to the completion of the interview. The interviews were authentic, raw and, sometimes, reflected the emotional experience of interviewing this population.

Memo 3: Analysis of the data set – Mabel
Date: 24-02-2018 I have decided to use the technique of incident-to-incident coding in all data sets. This will make it possible to compare the more similar incidents with other data sets without the 'bias' of the context in which the incidents were placed. After the initial open coding, I read the text again and looked for unique in-vivo codes/quotations. The in-vivo codes/quotations I found were unique in the story of the participant. Therefore, I have searched for specific words in MAXQDA 'punishment' and 'husband'. With this search, I found comparable quotations, where the participant explains the same opinion but in different words. The next step was to verify my findings (the initial coding and the in-vivo codes) and, in preparation for comparing the findings with other data sets, I propose to write memos of each data set (this is the fifth one), according to the method proposed by Charmaz. Therefore, I took a new look at the complete interview, listened to the spoken interviews again and used the techniques as proposed by Charmaz, and with references to Glaser (1978). By using the technique of memo writing, I attempted to find new insights or confirmed the insights the initial coding gave me. Furthermore, I combined my field notes with the verbatim interview. This is the last data set-memo of the first interview session I have performed. It really gave me a good insight into the use of these steps, and subsequently to every individual data set analysis. I have noticed a smoother discovery of what is 'really going on'. And there is also a parallel process, that eating disorders are not about eating. Eating is the vehicle of one or more of the problems that the patients experience. The eating disorder is like a thick blanket where the real suffering is discovered underneath.

Providing a better grip on this process, I use the questions Glaser (as quoted by Charmaz, 2006) formulated:

- What is this data a study of?
- What does the data suggest?
- From whose point of view?
- What theoretical category does this specific data indicate?

Charmaz (2006) refers to the fact that memos can be used as a tool to compare data sets and this helps direct me towards further data collection.
For this memo I have listened to the recordings because I was very interested in the tone of the voice. Mabel's voice is soft and implicit, as though she cannot have a voice in her life. The tone suggests the feeling of not being important enough to listen to.

Memo 3: Example: Analysis of the dataset of Mabel.

6.5 The process of focused coding

The next phase of the analysis was the focused coding to allow the sorting and synthesising of blocks of data (Charmaz, 2006: p 57; Charmaz, 2008: p 164): (see also Section 5.3.2.6: Data collection- focused coding). Within this iterative process, I searched for the most noticeable themes by sifting through the early initial codings in their contexts. With this, I was able to check any preconceptions of the topic which may have developed. Therefore, I re-read the narratives and earlier memos, I combined and compared them with the early findings and with the conceptual categories illustrated in the mind map diagram (Diagram 1: Example of conceptual mapping). As a result, I was able to explore the various perspectives of the SE-AN sufferers, which made the earlier findings more robust, and allowed new categories to emerge. Furthermore, I sought alternate explanations for the earlier findings within the same context, which mainly resulted in finding different expressions for labelling the same early-category concepts (see Example 1 below), or by defining the direct opposites which had appeared in the same category (see Example 2).

Example 1: In the early conceptual category: Positive experiences and decrease of ED symptoms

- Being able to make new friendships
- Making new friendships

- Increasing interests in others

Example 2: In the early conceptual category: Contacts with caregivers:

- Trusting the psychologist / sharing her story with the nurses
- Opposite: Not being seen by caregivers / experiencing punishment by caregivers

Regarding the opposites, I considered that both perceptions could be placed in a ‘time continuum’, belonging to the same emergent theoretical category. To give a better insight into the process of focused coding, and the development of the theoretical categories, I designed a simple map, using the initial codings, which could be connected to the theoretical findings of ‘Guilt & Shame’ and ‘Recovery & Success’. I then sought connections between the early categories and gathered these together to justify the early theoretical findings I had discovered. I have visualised my thinking process in the mind map example below. This mind map, Figure 6.4, illustrates the emergence of the theoretical category ‘continuum of weight loss/gain.

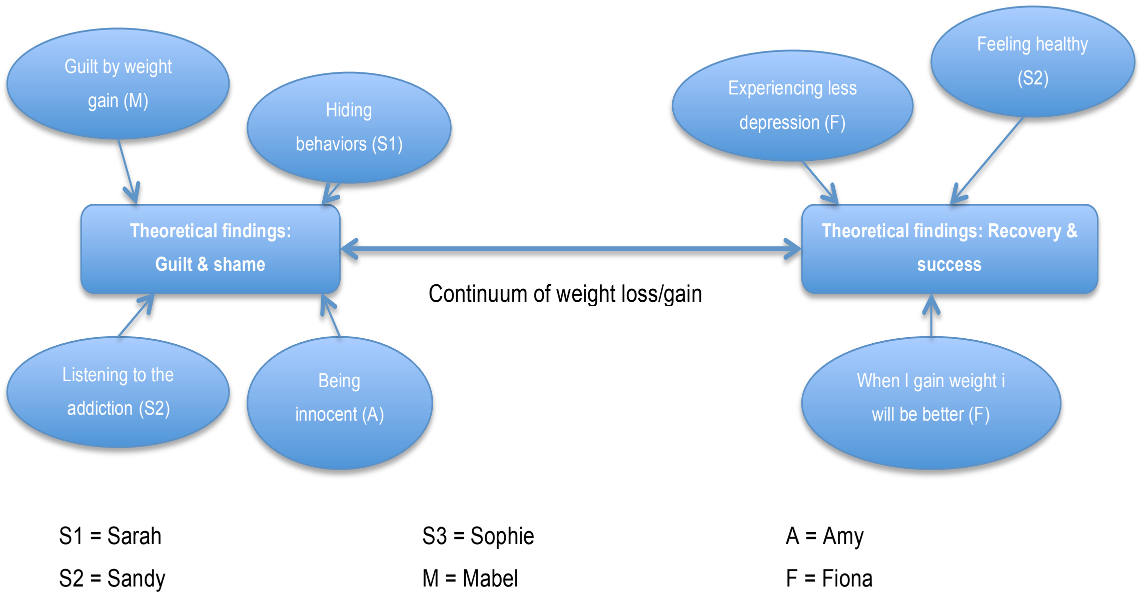


Figure 6.4: Emergence of the theoretical categories in the process of focused coding

In order to protect against bias, and to move the analysis towards the final theoretical categories, I arranged a meeting with the full supervisory team in Utrecht (17th to 19th April

2018). With this, all three of the supervisors were able to conduct simultaneous initial codings and could discuss the findings that worked towards a solid and rigorous approach. A comparison across all the data sets and the exploration of the theoretical possibilities were discussed, which led to a higher level in theoretical category development. The findings were defined and substantiated in the empirical evidence, which led to tentative theoretical categories. During this process, classic techniques were used. To this end, each team member (the supervisors and I) worked through the data sets on paper, theoretical categories were written out in messy mind maps on posters (see Appendix 6 - 6.4) and scrutinised for those who can *“carry the substantial weight of the analysis”* (Clarke, 2003 in Charmaz, 2006: p 139; Charmaz, 2008: p 164), According to Charmaz (2006), it means that raised categories include crucial properties to make the data meaningful, hence it strengthen the analytical process to ascertain if any of the categories are related to each other, which, in turn, helps to make the categories more robust which provides the ‘analytical momentum’ (Charmaz, 2006). Thus, theoretical categories emerged out of the focused codes. Figure 6.5 (Cycles in coding, Charmaz, 2007) illustrates a brief summary of this iterative process.

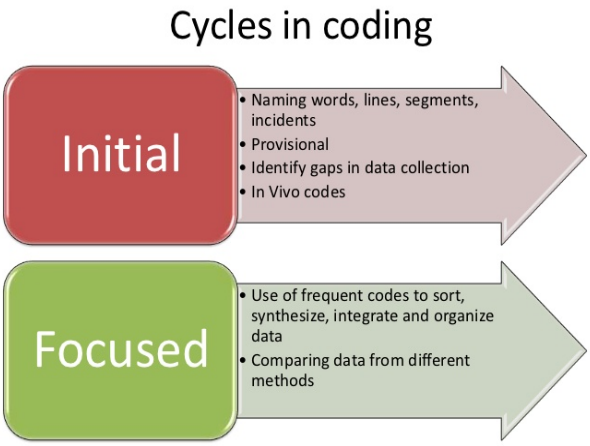


Figure 6.5: Cycles in coding (after Charmaz, 2007 - Slide 8)

With regards to the iterative characteristics in GT, in this section, an example of the iterative process as used in this project is described. In the area of focused coding, a new early category arose concerning the leading research question, which I have classified as ‘experiencing eating rules’. Although the phenomenon is not categorized as ‘new data’ in terms of the narratives, the phenomenon of ‘experiencing eating rules’ is most likely related to the experiences of daily living, and the quality of life is certainly crucial in the experiences of people living with SE-AN. Therefore, I decided to return to the study of the earlier data whilst focussing on this phenomenon. With this, I discovered the initial codings, which can be categorized as ‘eating rules’ in all the data sets, and decided to promote this as a separate early category, because of the major impact of the phenomenon in the daily lives of people with SE-AN (Charmaz, 2006).

6.6 The process of axial and theoretical coding

Guided by the early theoretical categories that I selected in the previous phase of the focused coding, I improved the meaning of the data, whilst focussing on the connection between the theoretical categories, in order to build a cohesive and integrated theory (Charmaz, 2006). In this way, I detailed the possible relationships between the several categories that emerged during the previous coding process. Glaser (1978) introduced this phase in order to conceptualise “*how the substantive codes may relate to each other as hypotheses to be integrated into a theory”* (Glaser, 1978, in Charmaz, 2006: p 63)[34]. In this major next step of the analysis in temporal ordering of the data, I decided to use a flexible approach for the ‘coding families’, as a refining step in the process of theoretical coding as adapted from Glaser (1978: pp 75-82) (see also Table 3). During the analysis, I discovered similarities in the coding family and my former categorizing, which I temporarily called a ‘group’ (see Diagram 1: Example of conceptual mapping. By using the ‘coding families’*,* it appeared to be possible to place the emergent data in their natural environment (the societal worlds), which made them evident and useful in this research. In the example below, I present an analysis of the theoretical category related to ‘suffering’ (Table 2).

---

[34] Section 5.3.3: Theoretical coding.

Table 3: Example of the theoretical category of suffering, using the coding families as adapted from Glaser (1978, in Böhm, 2004: pp 270-275).

Coding families	**Concepts**	**Examples**
The Six C's	Causes, contexts, contingencies, consequences, conditions	Of suffering: losing contacts, defining attention through the suffering, declined psychological functioning, declined physical functioning, loneliness
Process	Stages, phases, phasing's, transitions, passages, careers, chains, sequences	Several stages of suffering, on-going construct of suffering, different dimensions of suffering
Degree Family	Extent, level, intensity, range, amount, continuum, statistical average, standard deviation	
Type Family	Types, classes, genres, prototypes, styles, kinds	Types of suffering: physical pain, psychological burden, loneliness, experiencing negative emotions, feelings of loss
Strategy Family	Strategies, tactics, techniques, mechanism, management	Interaction with suffering, coping style: staying childlike, avoiding social contacts, contacts are made by continuous suffering, suffering provides contact within the services
Interactive Family	Interaction, mutual effects, interdependence, reciprocity, symmetries, rituals	Interdependency with suffering, suffering as a gain itself, maintaining contacts with healthcare workers, suffering is the communication
Identity-Self Family	Identity, self-image, self concept self-evaluation, social worth, transformations of self	Childish identity, dependent behaviours, loss of identity and lacks matureness
Cutting-point Family	Boundary, critical juncture, cutting point, turning point, point of no return	Starting point for a medical career as a Patient, suffering is a legal way to be seen as a patient
Cultural Family	Social norms, social values, social beliefs	Social norms according to tolerating suffering and non tolerating suffering as seen through the constructs of others, defining stigma
Consensus Family	Contracts, agreements, definitions of the situation, uniformity, conformity, conflict	Compliance: acceptance of the AN status according to suffering, adaption of the AN condition, suffering and AN are bread and butter

In the search for an overlap in the categories, I scrutinized the findings and placed them into a continuum of thinking patterns, as well as the experiences of the women, and the experiences of other relevant people, as seen through the eyes of the women. Next, I illustrated these in the figure below (see Figure 6.6: Example of Clustering Codings). The figure was guided by two insights: 1) The early groups I formulated in the earlier development of the initial codings. 2.) the 'coding family', after Glaser (Charmaz, 2006; Böhm, 2004). By including both insights into the figure, I was able to replace my early-formulated groups into the several 'families', which made the categories that had emerged earlier more robust. Then, the findings related to the previously-developed groups were added to the circles in the figure. With this, I was able to give meaning to the analytical interplay between the different categories, which strengthened the findings in the earlier stages. The following diagram (Figure 6.6) illustrates the analytical process. In the next section, I provide a more extensive explanation of the diagram below.

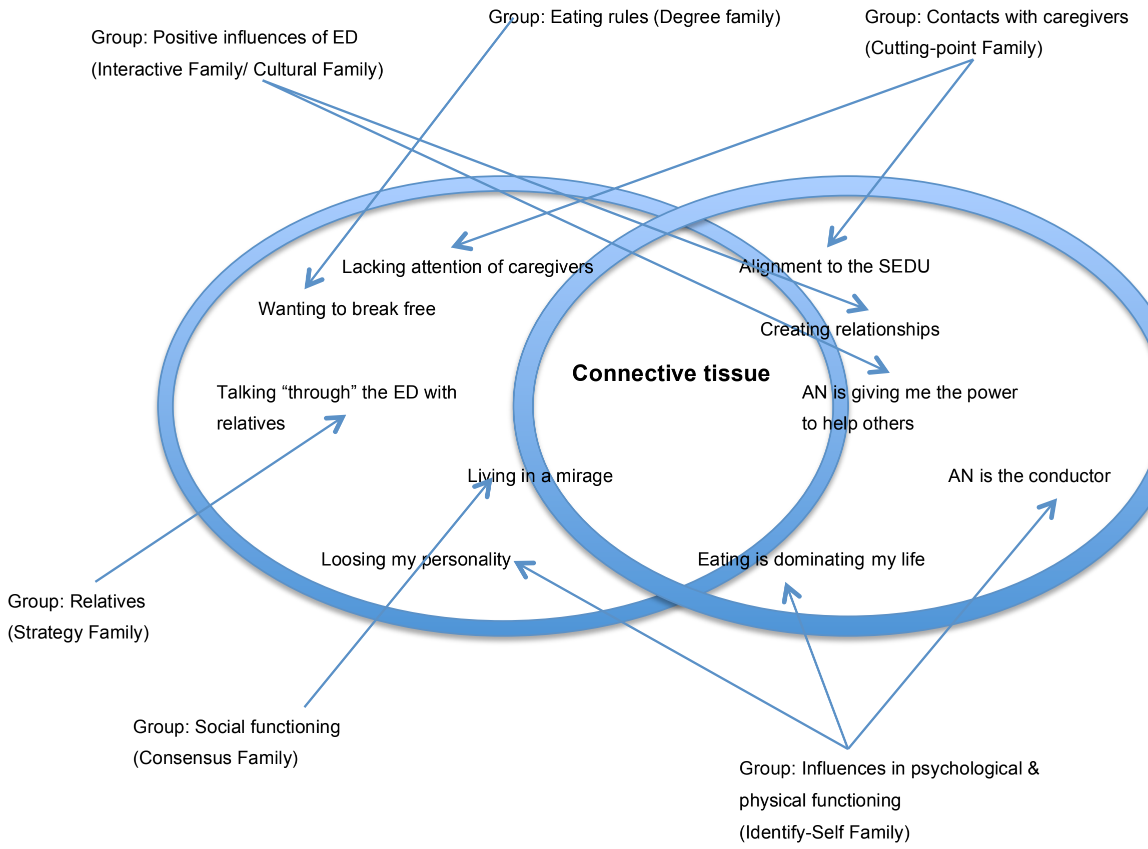


Figure 6.6: Example of clustering the codings in the search for theoretical development

Regarding the figure above, I present an explanation of the example referring to the analytical interplay within the categories, also as seen above (Figure 6.6). The left-hand circle illustrates the current, mostly negatively, thinking patterns of the women, as well as the experiences of others, as seen from the perspective of the women SE-AN sufferers. Moreover, it identifies dependence. For instance, '*talking through the ED with relatives'* is a coding, which emerged in the 'Relatives' group and can be defined as a 'strategy in the coding family' [35], since it can be seen as a coping style of the women (Glaser, 1978). The right-hand circle clustered the

---

[35] Table 3: Example of theoretical category of suffering while using the Coding Families as adapted from Glaser (1978, in Böhm, 2004: pp 270-275).

codes relating to more positive self-perceptions with regards to the eating disorder condition, and furthermore, it clustered the connection between current thinking patterns and the women SE-AN sufferers' own past experiences with regards to the topic of this research. An example of the coding: '*AN is giving me the power to help others'* is categorised in the group as 'Positive influences and decrease of ED symptoms', which is defined as a 'Cultural Family', because of its social value (Glaser, 1978). In the overlap of the circles, a certain tension is demonstrated, in terms of how the codings and the categories attach to each other. In this example, the theoretical category of '*The connective tissue'* appeared, which serves as the connection between the early groups, and thus, the coding families (Glaser, 1978). Whilst conducting the theoretical coding, tentative formulated codings became more robust and contributed to building a more solid theory. In one of the memos (Memo 4: Exploration of connective tissue), I give meaning to the phenomenon of connective tissue in the lives of the people with SE-AN.

Memo 4: Exploration of connective tissue

Regarding the SEDU, daily talks and actions are often related to eating, weight, calories, and the difficulties according to food issues. Hence, there are a lot of chats with the professional cooks about the preparation of meals. Also, with the nurses, there are often discussions which refer to the amount of calories, and of course, the same discussions are repeated with the therapists, that is the place where all the topics come together to discuss them. Talking about food and eating became "bread and butter". Then, literature related to eating disorders refers to persistent ruminations pertaining to weight, food and body shape, (Touyz et al., 2013) and it is precisely these beliefs that are inextricably linked to people with SE-AN. During conversations I had with the SEDU patients, I often invite them to explain what they did for a hobby before they became ill. Or, I attempt to talk about the news, like what is going on in the outside world. And I noticed that people do not know, or are not that interested. It is like the news simply does not reach them, or hobbies that they used to like, or books, music, work, it became vague. I can summarize lots of actions where people have lost interests. I my view, the eating disorder as connective tissue in talks is a significant theoretical category and it might explain how people can hold on to their daily routines in each facet of it. The ED manages uncertainty, instead of experiencing a total lack of control, the ED provides the person a ED personality, in terms of: on one hand, being an ill person where to care for, and on the other hand; it creates the personality who knows exactly what to do as long as it is connected to eating behaviours. Thus, regarding these findings, the theoretical category of 'connective tissue' is especially worth it for further exploration.

Memo 4: Exploration of connective tissue in the search for theoretical development

6.7 Theoretical saturation

Theoretical saturation in this project is understood as a signal that the study is complete. That is, when no fresh data has occurred during the data analysis; new narratives no longer deliver fresh codings and; regarding categories, no new issues arise (Bowen, 2009). Glaser & Strauss (1969: p 62) stated that saturation can never be reached by studying one single incident in one group, although there will be the discovery of some basic categories, referring to a few properties. Thus, sample size is increased when data are saturated (Glaser & Strauss, 1969), which is equivalent to the sampling approach taken by Bowen (2008). Theoretical saturation generated a maintainable theory, which is relevant to the field of study (Glaser, 1992), although, in research practice, it is debatable as to when the exact moment of saturation is arrived at (van Staa & Evers, 2010). Böhm (2004) and Bowen (2009) both stated that theoretical saturation is a pragmatic decision, which is difficult for novices to make in the field of Grounded Theory in which saturation is rooted. In her work, Bowen refers to Hyde (2003, in Bowen, 2009), stating that a Grounded Theory approach emphasizes more rigorous data comprehension, although there is no formula as to when saturation is reached. Furthermore, Böhm (2004) recommended teamwork and supervision being intertwined into the GT method. With this in mind, I decided to discuss the topic within the supervisory team to give meaning to the actual point of saturation. One of the outcomes of the discussion was that, in a constructivist approach, it is not the proliferation of findings that increases the external validity of the study, increasing the sample size is an assumption that resonates in more positivistic research (Vickers, 2016), but a constructivist approach encourages giving meaning to the concepts and categories, with a view to integrate them into a consistent theory (de Boer, 2011). Sandelowski (2000, in Howarth, 2012) stated that a greater focus on the topics and the search for appropriate participants is more relevant than the sample size or the number of participants. Charmaz supports this view that an ‘appropriate’ sample size of participants increases the affectivity and relevance of the categories, rather than a large sample size (Charmaz, 2003 in Bowen, 2009).

As this study takes a constructivist approach, a diversity of analytical techniques was used until the theoretical adequacy was reached. The initial coding explored the theoretical possibilities and helped me to discover the 'gaps in the data'. With this, I was able to both reflect on the data, and know how to conceptualise it. The initial codes were then used to make primary minor theoretical categories. Once the theoretical categories were determined, the constant comparative method supported the categories with additional codes. The performance of the axial codes, along with the comprehensive memos made the theoretical categories definitive in terms of the achievement of theoretical adequacy. In order to make this process explicit, I refer to the Flowchart of The Grounded Theory Process[36] (Charmaz, 2006: p 11).

6.7.1 The theoretical categories

The data analysis identified four main categories, which revealed the process of how people with SE-AN experience their life. The categories, and their properties and dimensions, are presented in subsequent chapters. These categories, directed by the leading research question, are as follows:

1) '*Suffering, but not in silence'*;
2) '*One step forwards, one step backwards'*;
3) '*Connective tissue'* and;
4) '*Best friend & Best enemy'.*

To build on a robust theory, I have chosen to divide each main category into a separate chapter. In the next chapter (Chapter 7: An exploration of the category 'suffering, but not in silence', and its phenomena), I explicitly describe the properties, the specific conditions and the dimensions of the phenomena as observed in people with SE-AN. This process of research demonstrates the insight into the inductive data gathering, and the analysis of this approach in the construction of a theory (Polit & Beck, 2011: p 412; Charmaz, 2008: p 155).

---

[36] Paragraph, 4.4.7: Integrating findings

6.8 The literature review method

As explained in Chapter 3 (Section 3.2: Introduction of the Literature Review), I determined to delay the literature review (Glaser & Strauss, 1967; Glaser, 1978; Charmaz, 2006). Nevertheless, in the pursuit of transparency, in this section, I explain the methodology according to the literature review.

Referring to the work of Charmaz (2006) in Chapter 7 ('Constructing Grounded Theory') an appropriate explanation of how to use the literature findings was found (Charmaz, 2006: pp 163-168). In this chapter, I decided not to use a rigid standard format according to inclusion and exclusion criteria (Charmaz, 2006). However, in my attempt to remain transparent, I added a diagram, whereby I attempted to create a transparent approach which is related to the direct findings and the subjects as processed by this project (Charmaz, 2006). Next, the assessment and critique of the findings will be conducted by the explanation of my ideas, which is further elaborated on in the discussion chapter (Chapter 11). In addition, Chapter 11 also includes the defining of already existing knowledge, whereby the reader of this work will be challenged for a theoretical discussion. Finally, I will explain how my theory will fit in with or extend the current literature (Charmaz, 2006: p 167). This will also be elaborated upon and included in the discussion chapter.

The guidelines as described above (Charmaz, 2006) have led to the following decision. Regarding the empirical literature, I included those studies that made use of a solely qualitative approach with a focus on SE-AN; the QoL within eating disorders; studies reflecting on the discovered findings within this research; and feminist approach studies which focused on eating disorders. No time limitations were used. The search for appropriate studies also revealed two quantitative studies which is why I decided to include them. Furthermore, the following databases were used: Google Scholar, Google, Pubmed, Psycharticles, EBSCO and Cochrane. Studies were included that met one or more of the search conditions; that are clearly written; that show clear key findings, and if they have been conducted by experienced scholars in the field of eating disorders. Next, the supervisory team also provided me with additional relevant literature.

In the literature search, the following search terms were used: '*chronic', 'Anorexia Nervosa', 'severe and enduring' and 'quality of life'*. These search terms were combined by using the Boolean 'AND' in search machines, combining the direct discovered key findings separately as described in the analysis chapters 7, 8, 9, and 10 as illustrated in table 4 underneath; The terms as used in the literature search.

Table 4: The terms as used in the literature search

Search terms as used in the literature review	'AND'
Anorexia Nervosa AND Severe and Enduring	Childlike behaviour; mental illness; stigma; craziness; self image; addiction; innocence; guilt; shame; reciprocity; reality; identity; communication; anorexic voice; personification; therapeutic relationship
Anorexia Nervosa AND Quality of Life	Childlike behaviour; mental illness; stigma; craziness; self image; addiction; innocence; guilt; shame; reciprocity; reality; identity; communication; anorexic voice; personification; therapeutic relationship

Further limitations in the search for literature sources were: English and Dutch language only, and, in addition to the empirical papers, I also included a range of personal scholarly books in the literature, I utilised the experience or unique insights of other scholars, along with the use of a clear writing style. My familiarity with the field of study also guided me. In order to provide empirical findings for the current study, and in the acknowledgment that little knowledge is available on the topic, I allowed myself to use 'grey sources' (the non-academic sources), such as specific internet sites, or brochures, or articles in the newspaper, referring to the topic of study (Glaser, 2007; Wessels, 1997). Then, the literature search was from October until December 2018. To give an appropriate insight in this search, I have visualised my decision-making process in respect of the literature review in the prisma chart below (Figure 6.7):

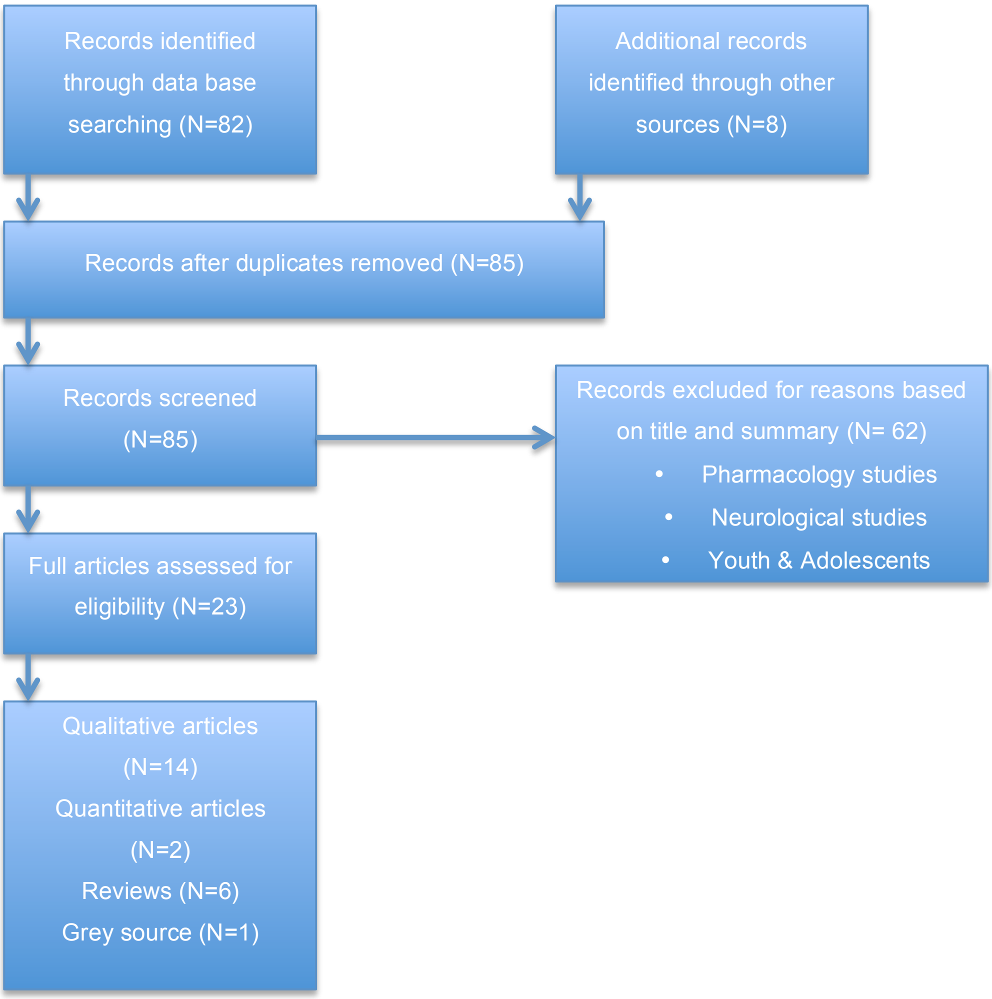


Figure 6.7: Prisma chart of the literature findings

In the figure (6.7) above, I have provided a flow chart detailing my decision-making process. By doing this I gained an insight into my thought process and search strategy, which contributed to the transparency of the constructivist approach utilised. In the attempt to provide the transparency, I included the literature findings as found in the scientific databases and other important sources which were used in the literature review section (Chapter 11, Discussion). Although Charmaz (2006, pp 163-168) states the use of relevant literature sources, she does not offer a clear overview as to how to reject or include extant literature sources, hence, I have used the Qualitative Assessment and Review Instrument (QARI) after

Briggs (2007, in Hannes, 2010) in my attempt to be transparent during the review. The QARI was developed to realize a systematic identification, evaluation, and synthesis of relevant literature (Hannes, 2010). In this study, the QARI supported me when sifting through the amount of literature found, whilst focusing on consensus regarding the methodology and the research question of the studies as well for the objectives and the gathering of data (see also: Chapter 11, Discussion, Section 11.2; Discussing the core category: suffering, but not in silence).

Then, the QARI appeared to be supportive following the research methodology and the rendering of data and the interpretation of results. Finally, the QARI was helpful in the discovery of the cultural or theoretical orientation of the researcher(s); the potential influences of the researcher(s) on the research process; the adequacy of the participants represented; the ethical approval; philosophical perspective and the grounding of the analysis of data the studies presented.

6.9 Summary

In this chapter, I have described the analytical process that was conducted. Therefore, I ‘identified’ the women (by means of pseudonyms) and included a brief summary of my personal impressions of the women in order to make the reader familiar with them. By these means, I have given transparency to the study, and I have confronted the issue of the credibility of the research, as well as the method. Moreover, this allowed the rigour of the study to be maintained, which is relevant in this type of study design.

I then presented the data analysis, guided by the constructivist method (Charmaz, 2006; Charmaz, 2008), and as influenced by Glaser & Strauss (1967). Overall, in terms of this constructivist theory, a flexible approach was used. In the first phase, the initial codes were used to make the primary minor theoretical findings. Next, I merged several techniques, which were: (i) line-by-line coding and the diagramming of the early findings; (ii) utilizing a mind map;

and (iii) writing the memos of each narrative, whereby I used the technique of incident–to–incident coding. Following the initial coding process, I worked on the focused and theoretical coding, in order to move towards the data analysis. A major event for scrutinising the data was planned for a meeting with all three of the supervisors, who participated in the simultaneous coding. This exercise helped to prevent against bias within the research, and brought the analysis towards the actual theoretical categories. The theoretical categories were systematically tested by means of the axial coding and the memo writing to test if they could *“carry substantial analytical weight”* (Clarke, 2003 in Charmaz, 2006: p 139; Charmaz, 2008: p 164). The theoretical adequacy of the saturation of the findings was then elaborated on, and these elaborated theoretical categories were then discussed. Finally, I illustrated the strategies used to gather the extant and relevant literature findings. In the next chapter, I examine the study’s findings, by referring to the category of ‘suffering, but not in silence’.

Chapter 7 ‘Suffering, but not in silence’

7.1 Introduction

In this chapter, I elaborate on the development of the theoretical categories, and I present the study findings, as revealed by using the approach set out in the previous chapters, 4[37] and 6[38]. A constructivist approach aims to present a cohesive and logical theoretical rendering by those who describe and explicate the experience of the phenomenon (Charmaz, 2006). In this chapter, firstly, I present the insight gained from the process of generalising the data and from the analysis. Following this, I then present each theoretical category in a separate chapter, which will be Chapters 7, 8, 9 and 10. Each theoretical category presented is underpinned by the theoretical findings. The theoretical findings originated from the initial codings, which I have framed within subthemes, which appeared in the earlier conduct of the iterative process. In the previous chapter (6), the theoretical categories emerged in the search for empirical underpinnings, by making comparisons and interpretations of the significance of the findings, which make them relevant to the data (Glaser & Strauss, 1969: p 91). The theoretical constructs are, however, often criticised as questionable, and this can detract from the credibility of the theory (Gasson, 2004; Wheeldon, 2009). Thus, it is reasonable for me to provide an explicit insight into the analytical process and the techniques used, along with the relationships between the data elements explored.

The data analysis resulted in the construction of four main categories, which, in turn, revealed the process of how a person with SE-AN experiences their lived life. The categories, directed by the leading research question are as follows:

1) ‘Suffering, but not in silence’: this category addresses the eating disorder functions as the non-verbal communication in people with SE-AN.
2) ‘One step forward, one step backwards’: refers to the meanings of people with SE-AN regarding the time continuum of weight loss versus weight gain. The issue of gaining weight is highly relevant to success and recovery, and to the

---

[37] Chapter 4: The fundamental methodological steps of GT according to Charmaz.
[38] Chapter 6: The analysis of the data

acceptance of responsibilities in adult life, and, moreover, to success in giving and receiving love.

3) ‘Connective tissue’: which is involved with the connection between people, their reality and the healthcare services.
4) ‘Best friend, best enemy’: this category refers to the positive attribution of the eating disorder versus the negative effects which are to be expected when referring to the recovery process.

7.2 The construction of theoretical categories

Although Strauss offered a more rigorous use of the guidelines, as described in the 1990 edition of Strauss & Corbin’s handbook, according to Kearney (2007, in Charmaz, 2008), this was motivated by numerous graduate students of Strauss, who exerted pressure on Strauss to make the administration of GT more concrete and rule bound. Nevertheless, Charmaz advocates the flexibility of the use of constructivist GT, (Strauss & Corbin, 1994, in Charmaz, 2008: p 168). Charmaz stated that it is the flexible nature of constructivist GT which creates the conditions to develop the theoretical categories, as opposed to using rigid and over-systematic guidelines. Furthermore, the iterative process generates an in-depth analysis, which is supported by insights which arise throughout the writing process, as well as sorting the memos, whereby the process of decision making can be elucidated (Charmaz, 2006). With this in mind, I considered the transparency of this project as even more important in terms of my responsibility to reflect the validity of the research. Thus, the following step was to gain an insight into the decision-making process of data generalising and analysis.

In the illustration below (Figure 7.1), I present the insight into how I addressed my decision-making when conducting the data generalising and analysis. To generate the findings and to make them more reliable, I wrote the memos, whereby I elaborated on my thoughts and discussed them, together with the findings, with my supervisory team, by email and during the face to face meetings on Skype. Furthermore, I supported the findings and my thoughts through observations on the SEDU. Regarding these actions, in the illustration below, I refer to them as ‘on site interactions’.

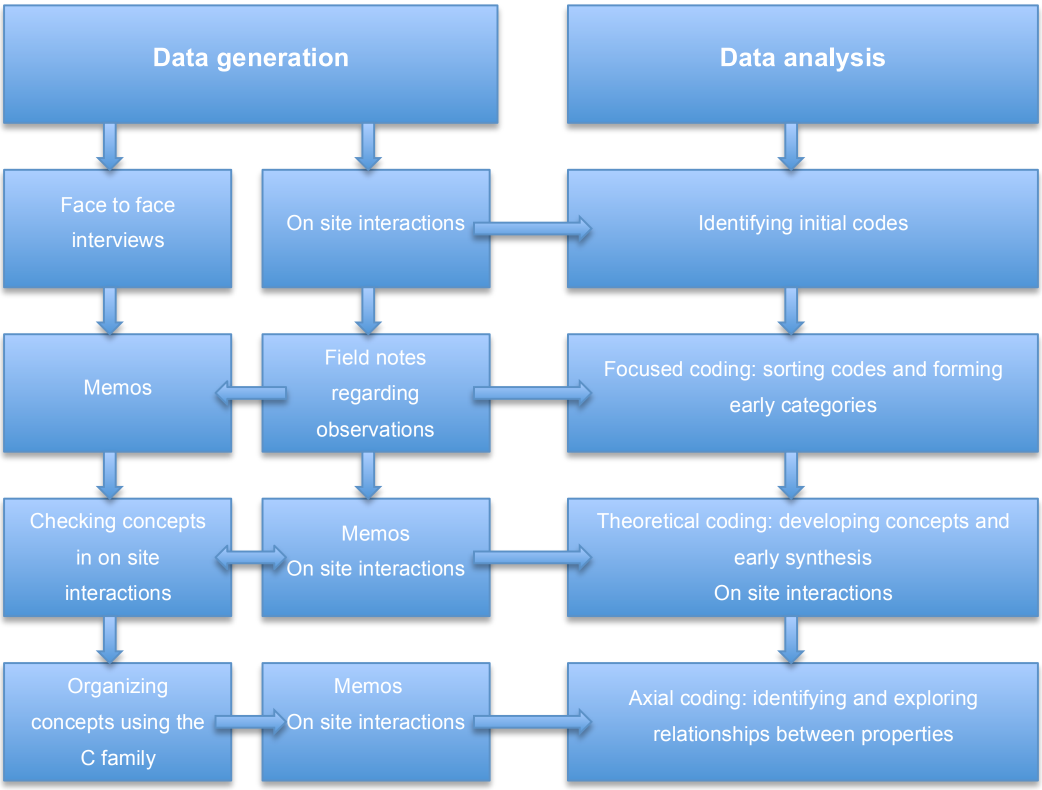


Figure 7.1: The process of data generalising and analysis

7.3 ‘Suffering, but not in silence’

The first theoretical category I present is the category of ‘suffering, but not in silence’. This theoretical category recognised the core findings of ‘*Staying childlike’* and ‘*Being seen as a psychiatric patient’,* the influences of SE-AN on *‘Self*-image’, and finally*, ‘Addiction’*, through the analysis of the multiple suffering elements of the SE-AN condition. Conversely, the suffering itself stands for a way of communicating. To give explanation to the category, I have chosen to explore the theoretical findings which appeared during the focused coding process. These findings explicitly give meaning to the ‘construct of suffering’ in the women SE-AN sufferers. Regarding the other main categories, the category of ‘suffering’ is incorporated within other important domains of life, in terms of the social functioning of people with SE-AN. I present the actual experience of the ‘state’ of the women with AN, with regards to the psychological and physical functioning, their coping style in relation to SE-AN, and finally, this category of suffering is related to the other main theoretical categories. To clarify the properties of this theoretical category, the technique of axial coding was carried out (see Figure 7.4: Axial coding of suffering (after Strauss, & Corbin 1990).

Although the main categories are closely related to each other, and are thus predictable, since we live a complex and layered existence, separating out the experiences as described is not wholly possible. For example, the category of 'the connective tissue' is related to the 'suffering, but not in silence' category, and the findings refer to both main categories, to the initial codings and to the later developed theoretical findings, which underpin both categories, and, in turn, they 'bridge the gap' between the main categories. In conclusion, there is a clear cross-interaction between the main categories. Both are located between the interactions of other early findings and categories. The illustration below (Figure 7.2) suggests the connections which exist between the main categories and is developed by using a 'messy mind map' construction. This enabled me to think beyond the observable micro-social structures, which made it possible to reveal the larger social constructs evident in the data (Clarke, 2003, in Charmaz, 2006):

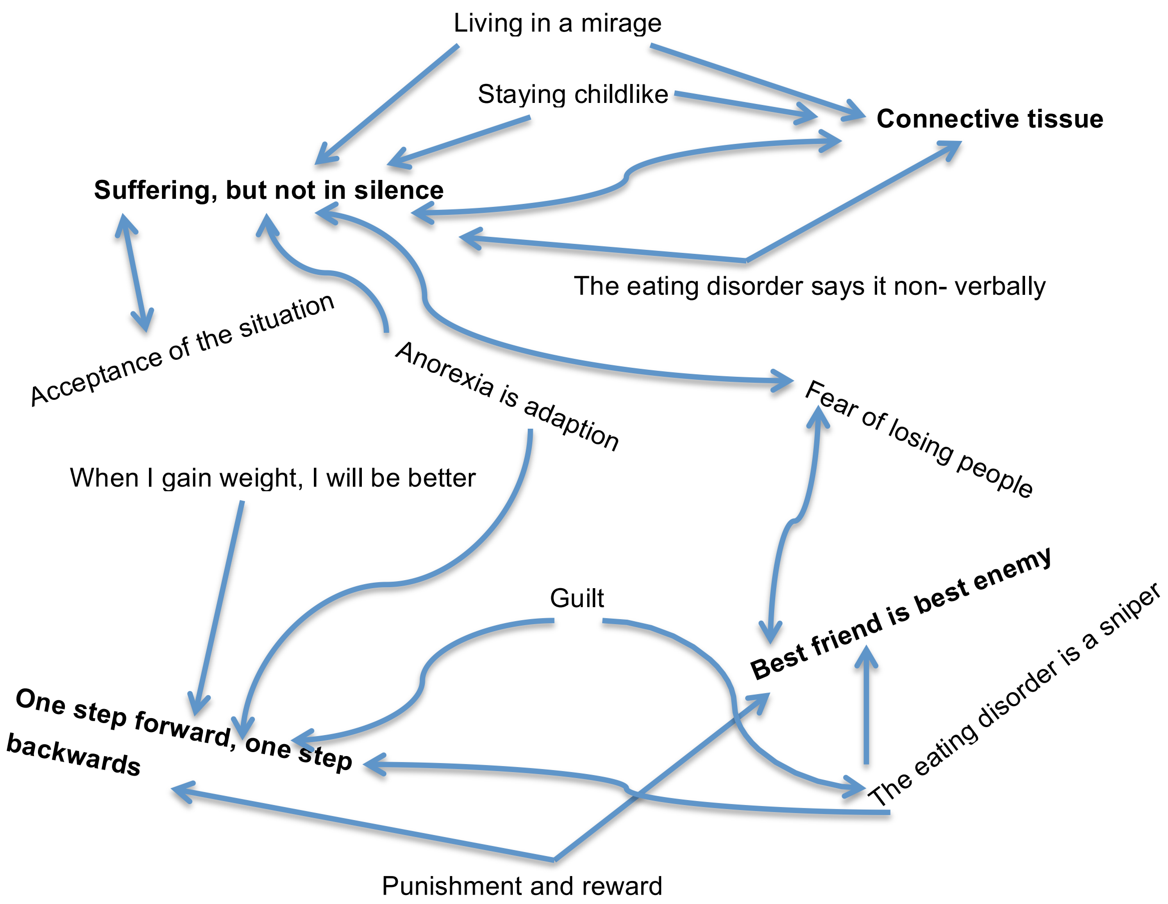


Figure 7.2: Messy mind map presenting the connection between categories

In the exploration of the data, it appeared to be helpful to frame the findings. Such exploration identified ‘immature behaviour’, ‘communication problems’, ‘(self-) stigma’ and ‘convictions’, which were all given and supported by the constructs of others, or prompted by the women themselves. Furthermore, the narratives referring to the topic of ‘suffering’, revealed the difficulties in the relationships within the family, the social contacts and the health care professionals, influenced by prejudgment of themselves and the constructs of their social environment. Overall, the initial codes referred to the phenomenon of ‘not taken seriously’, ‘expectations in behaviour according to others’ and ‘being side tracked’, which led to the development of the main categories. In addition, situations where the treatment process was discussed with professionals also explored feelings of ‘uncertainty’.

To progress the theoretical momentum, diagramming a mind map was produced during the face to face 3-day meeting with the supervisory team in April 2018 (Wheeldon, 2009; Charmaz, 2006) in order to locate and to organize the focused codings, which are underpinned by the initial codings. Wheeldon (2009) does not strictly recommend a 'one size fits all' concept for a mind map, though the main goal of presenting a mind map is to give a clear insight into the thinking strategy of the researcher. This increases the credibility and the transferability of the constructivist approach (Hoepf, 1997, in Wheeldon, 2009), which is built on subjective constructs. The conducting of the simultaneous coding and discussing the findings explained the focused codings. In this particular exercise, the main findings of each of the women with SE-AN were written out on a large sheet of paper. Next, during the constant comparison method, the team worked through all the data sets and explored the theoretical possibilities, which were then discussed, and which led to the elaboration of a higher level of concepts. The findings were defined and substantiated by the empirical evidence, which finally led to the tentative theoretical categories. During this process, a few classic techniques were used. All the team members[39] worked through the data sets on paper, theoretical categories were written out in several messy mind maps in poster format and the theoretical findings were developed by the addition of the initial codings (see example in Figure 7.3: illustration of a messy mind map). The messy mind map, as given below, is a copy of the original messy mind map (Appendices 7, 7.1, 7.2, 7.3 and 7.4). In the illustration below, the focused codings are printed in bold, and the arrows suggest a connection between the initial and the focused codings. The initial codings are given a capital letter, which suggests the empirical findings in the narrative, and corresponds to an anonymous forename (see index). The focused codings are printed in bold and suggest the underpinning for the (early) theoretical category. The (early) theoretical category is surrounded by a blue line.

---

[39] Myself and the supervisory team together.

Index

Fiona:	F	Sarah:	S1
Mariah:	M1	Sandy:	S2
Mabel:	M2	Sophie:	S3
Violet:	V	Amy:	A

Figure 7.3: Messy mind map exercise to locate and organise focused codings

After processing the theoretical momentum, it was especially relevant to explore the subthemes of the concept of 'suffering', and how these findings relate to each other. Thus, to define the properties of the main category, and to check specific findings, the axial coding was used, which demonstrated the fractured codings re-assembled [40](Glaser, 1978; Charmaz, 2006). Understanding the data is not intuitive (Scott, 2004), but subsequently, the data

---

[40] 'Fractured codings refers to Charmaz, 2006: p 60; Glaser, 1978, in Charmaz, 2006: p 63

emerged by asking myself the following questions, which were led by the following openings: *'what', 'how', 'when', 'where', 'why'*, along with the premier question: '*What are the consequences of the process?'* (Glaser, 1978; Charmaz, 2006, p 51; Scott, 2004). Furthermore, in defining the theoretical categories, I often used the women's own words, which appeared to be helpful in the protection of the project against bias (Scott, 2004). For this reason, I placed the initial codings in a text balloon in the model below (Figure 7.4 to support and to give insight into the theoretical findings. The illustration (Figure 7.4 elucidated the findings and framed them in a continuum of acceptance according to suffering, by using Strauss & Corbin's (1990) approach.

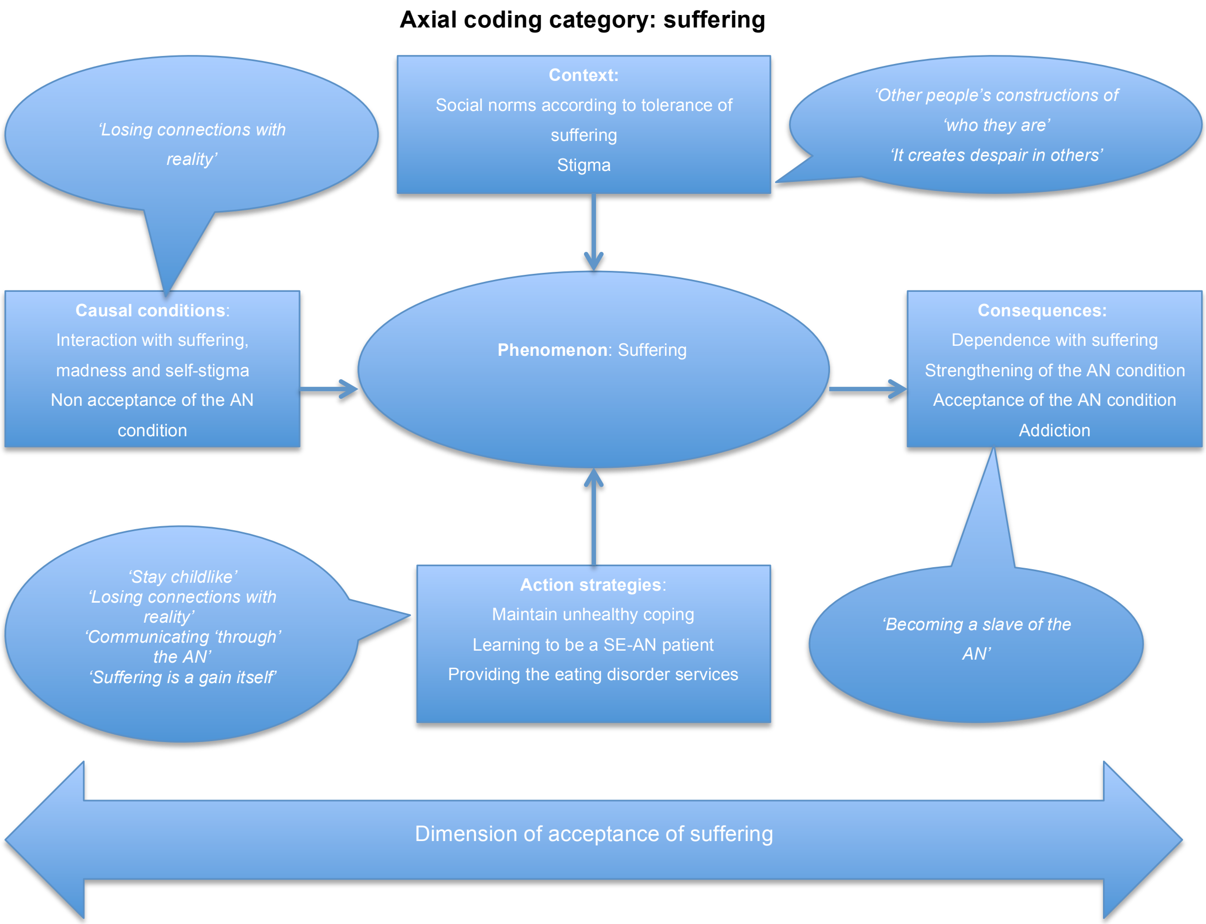


Figure 7.4: Axial coding of suffering (after Strauss & Corbin 1990)

Regarding the model above, I worked out the findings schematically, which led to an overview of the properties of the main theoretical category. In the section on 'consequences', this example revealed the dependence and the continual strengthening of the AN condition. In the model, the arrow suggests a continuum of ‘acceptance of the suffering situation’. With this, I defined the main category of ‘suffering’. In conclusion, the axial coding visualised the fractured narratives as re-assembled again (Glaser, 1978, in Charmaz, 2006), which gave me an insight into the properties of the category and, in turn, this helped me to define the property of suffering in the women SE-AN sufferers.

7.4 Framing the properties

To frame the findings, I chose to expand upon the theoretical codes by using the coding family as developed by Glaser (1978) (see also Böhm, 2004). In doing so, I was able to explore the overlap and the connection between the early findings during the initial coding process and the formation of the early categories. This way of working corresponds with the axial and theoretical coding[41] and proved to be a helpful tool in dealing with the amount of data, although working with the coding family matrix turned out to not be too rigid. Figure 7.5 below, explains the insight by means of the coding family classification, which I used, after Glaser (1978).

---

[41] Section 6.6: The process of axial and theoretical coding.

Coding families	Concepts	Examples
The Six C's	Causes, contexts, contingencies, consequences, conditions	Of suffering: losing contacts, defining attention through the suffering, declined psychological functioning, declined physical functioning, loneliness
Process	Stages, phases, phasing's, transitions, passages, careers, chains, sequences	Several stages of suffering, on-going construct of suffering, different dimensions of suffering
Degree Family	Extent, level, intensity, range, amount, continuum, statistical average, standard deviation	
Type Family	Types, classes, genres, prototypes, styles, kinds	Types of suffering: physical pain, psychological burden, loneliness, experiencing negative emotions, feelings of loss
Strategy Family	Strategies, tactics, techniques, mechanism, management	Interaction with suffering, coping style: staying childlike, avoiding social contacts, contacts are made by continuous suffering, suffering provides contact within the services
Interactive Family	Interaction, mutual effects, interdependence, reciprocity, symmetries, rituals	Interdependency with suffering, suffering as a gain itself, maintaining contacts with healthcare workers, suffering is the communication
Identity-Self Family	Identity, self-image, self concept self-evaluation, social worth, transformations of self	Childish identity, dependent behaviours, loss of identity and lacks matureness
Cutting-point Family	Boundary, critical juncture, cutting point, turning point, point of no return	Starting point for a medical career as a Patient, suffering is a legal way to be seen as a patient
Cultural Family	Social norms, social values, social beliefs	Social norms according to tolerating suffering and non tolerating suffering as seen through the constructs of others, defining stigma
Consensus Family	Contracts, agreements, definitions of the situation, uniformity, conformity, conflict	Compliance: acceptance of the AN status according to suffering, adaption of the AN condition, suffering and AN are bread and butter

Figure 7.5: Coding Family Matrix of Suffering (after Glaser, 1978)

By using the coding family technique, which is clarified in the figure above (7.5), insight was gained into the several 'family types', which influence the quality of life, in terms of the property of 'suffering' that was examined. The mutual findings correspond with the findings as revealed in the following figure (7.6) below, as showed in the boxes in the figure. Regarding the category of 'suffering', the following four properties are elaborated on in the following sections. In the figure, corresponding to the second row, Box 1 frames the first property, which is, 'I will always be the girl with the eating disorder'. This property is closely related to the second property of 'self-image', which I considered as the second property, and placed underneath. Box 2, then, suggests the framing of the third property and elaborates on 'mental illness & stigma'. The fourth property includes 'addictive behaviour'. Next, the 'dependence with suffering' property, as framed in Box 3, suggests the effects of the earlier elaborated categories. This category is related to the ‘strengthening of the AN’ category, which is considered as a result of the duration of the suffering, as seen in the constructs. Thus, the ‘dependence with suffering’ category is not a property in itself, but is developed ‘through’ the disclosure of other properties.

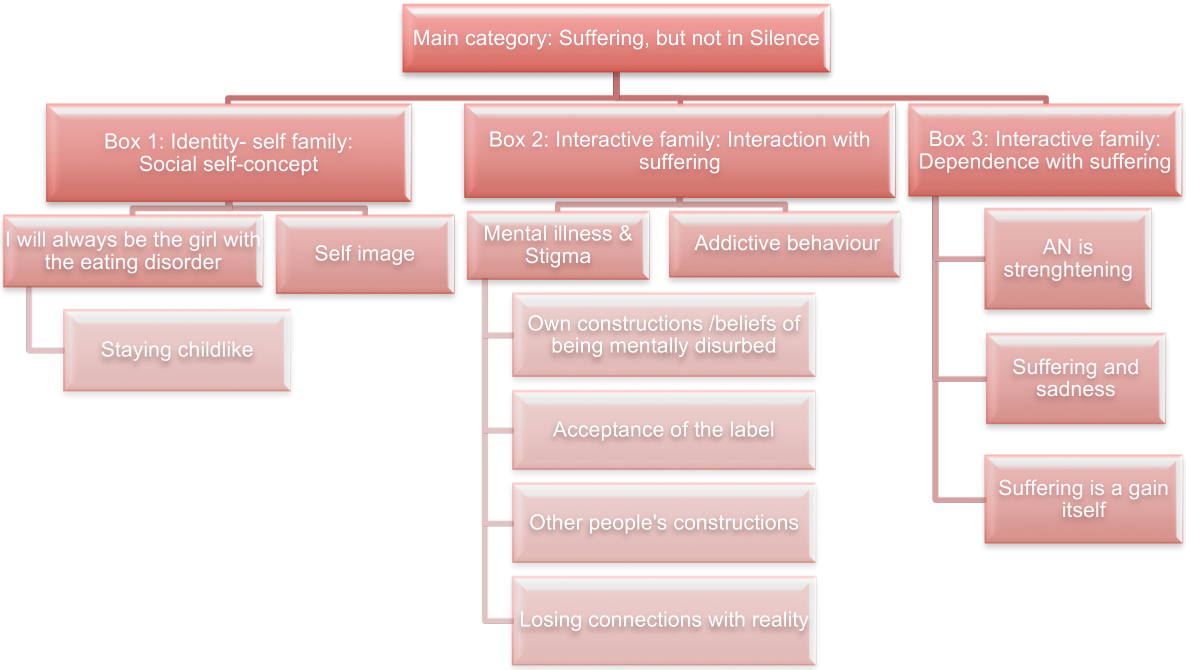


Figure 7.6: Diagramming properties through the coding family (Glaser, 1978)

7.5 Exploring properties and dimensions

7.5.1 The exploration and dimensions of the first property, ‘I will always be the girl with the eating disorder’

Making the findings evident and grounded, I present an explanation of each separate property, together forming the main category of ‘suffering, but not in silence’, starting with the property of ‘I will always be the girl with the eating disorder’. The title of the property was chosen in accordance with the advice of the supervisory team during the 3-day meeting in April 2018, and directly refers to an ‘in vivo’ code of Sarah (L33):

"That's the girl with the eating disorder".

The construct as above 'carries the data load' of the property (Charmaz, 2006). In the interviews, several constructs pointed to 'staying childlike'. Either the women are longing for an immature approach, or the women construct the illusion of an immature approach, as seen through the eyes of their contacts. The constructs, such as 'wanting to be the little girl', 'not feeling mature' and 'treating me as a child', all refer to this phenomenon. Overall, such indications were sufficient to explore this area, given the impact on the quality of life. The following excerpts of narratives illustrate the contrasting phenomena, whereby there is a focus on a leading phenomenon, according to the stance 'I will always be the girl with the eating disorder', which can be seen in the extracts from the interview data below. Specifically, the words, *"I was a little girl for them"* (Mariah: L78) appeared as Mariah's construct, as is the powerful statement, which is as follows:

> *M: "The people were nicer for me because they weren't picking on me.*
> *I: And receiving an out-patient treatment, was it a positive experience finally, like, did it contribute to a decrease of ED symptoms?*
> *M: Yes, it was, my weight was higher, and the group was nicer. I was a little girl for them."*
>
> (Mariah: L76-78)

Similarly, Sarah reflected on her status as a 'girl', despite her real age being 28. This has become her identity and how she believes that others perceive her:

> *"And my family, they also want to take account of me, like, that's too much for her, we won't tell her. For me, that's difficult. And after all this, the whole world thinks, Oh, that's the girl with the eating disorder".*
>
> (Sarah: L66)

Violet reflected on her view of the approach of her parents, who considered her an immature person:

"I: I hear you say; I want to go, but your parents are saying, how? Is that difficult for you?
V: Yes, because my younger brother will leave the house soon and that's okay but it's not for me.
I: Do you compare yourself with your brother's situation? Do you think that your parents don't need to worry about you?
V: Yes.
I: Would you like to have some more independence?
V: Yes.
I: Despite the fact that you're ill?
V: Yes definitely. I chose to have an eating disorder."

(Violet: L282-289)

According to Mariah (L76-78[42]), she referred to a more comfortable situation during her first in-patient treatment. In her narrative, Mariah related her first in-patient recovery experience as being somebody who needed to be taken care of, as if she was a little girl again. Being treated as a little girl gave her comfort and the ability to not carry the responsibility that is appropriate for adult status. In her view, Mariah experienced the protection of others, as she was viewed as a girl instead of a woman, which made her position of being seen as a girl more comfortable. In this excerpt, Mariah made a comparison between gaining weight and being treated as a little girl. Initial codings, such as 'fighting for independence' and 'not receiving support of parents', were the influencing factors according to the perception of 'feeling safe in the child position'. Conversely, Sarah clearly stated her belief that her parents, as well other people, always approached her as *"the girl with the eating disorder"* (L33) (in vivo code), despite her age. With this, Sarah felt ignored in her adulthood, and felt that she did not get the chance to make her own decisions on several life domains, such as; work, living independently, hobbies, etc., because others made them for her. This belief is underpinned by the initial coding, 'feeling misunderstood by parents', and the 'in vivo' code, 'being the girl with the eating disorder'. The constructs of other people, which are discussed by the women, are related to certain feelings,

---

[42] Transcripts are available for scrutiny on request

raised amongst others. These can be related to ‘vulnerable’ and ‘the appeal of the SE-AN patient to be taken care of’. Furthermore, it became clear that other people approached the women’s situations as ‘sad’. Sarah’s excerpt (L66) is in accordance with that of Violet. Both excerpts were very similar to each other, whereby Violet felt she was treated as an immature person, mostly by her parents (L282-289). She wanted to have more responsibility, appropriate to her age, and she compared her situation with that of her healthy brother.

Thus, it is suggested that the women SE-AN sufferers have developed dependent behaviour, which can be seen through the lens of ‘staying childlike’, and it is suggested that the women gain attention from their social environment by means of their status of ‘suffering’. With this, the suffering is a medium to reach out to other people. However, contrasts are seen, as the women also construct the notion of *how* they are approached in terms of being an immature person.

Regarding the dimension of ‘I will always be the girl with the eating disorder’, Violet’s narrative exposed the issue of ‘not being able to maintain friendships’. This is supported by the initial findings, such as ‘avoiding social contacts’ and ‘judging the eating disorder’s habits by others’, which, in the case of Violet, is what has led to her keeping a distance, with regards to other people and activities. The following excerpts reveal these constructs:

> *"I want to study, or doing things most people my age do, like going out, dating, visiting festivals, all those kind of things. It’s not that I wanted to do all of those things always but I noticed that the eating part obstructs me in everything. And, the exercising that I always have to do, that makes it difficult to meet other people".*
>
> (Violet: L41)

And later, in the same interview, Violet referred to a former situation, which was very painful for her:

> *"I felt ashamed for my eating behaviour, but it has its roots in my past. When other people saw me eating, I always received very negative comments, like, I was a guzzler, and I’ve had a big fat tummy, and I didn’t need all the food. And now I think; that is something from the past, but still, my thoughts are always focused on that topic".*

(Violet: L111)

In Violet's case, her construct clarified 'bullying' by other children and her family, by referring to her former eating habits (L111). Violet learned to keep a distance, in an attempt to protect herself against emotional hurt. In this way, combining her severe AN condition and her relatively young age, she made herself dependent on her parents. Initial underpinnings, such as 'keeping others at distance' and 'others are condemning me', made the data grounded. With this finding, it is suggested that the role of 'staying childlike' functions as a protector against emotional hurt.

To gain an overview and transparency in the process of developing the property, inductive reasoning was utilized. Thus, I designed a matrix, Figure 7.7, in order to present the inductive process. The figure below represents a frame of the findings, which is related to the property, 'I will always be the girl with the eating disorder'. Hence, the findings are related to each other. This figure is best understood if viewed from the left- to the right-hand side in terms of the inductive rationale.

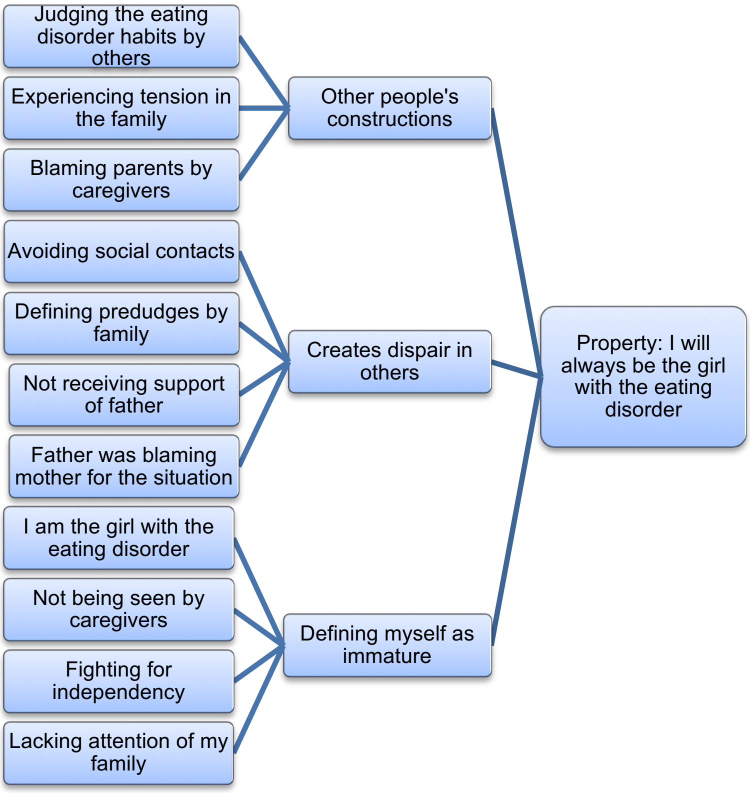


Figure 7.7: Framing the fractured codings into the main category

Thus, the insights from the narratives appeared as significant as the women assumed to '*know'* how they are approached and '*how'* they see themselves. During the constant comparative analysis, a relationship was formed between the women's personal convictions and the perception according to the immature approach other people are demonstrating. It became apparent that the women not only comply with the notion of 'suffering' but they also expect others to comply with this idea of 'suffering' when in contact with the women with SE-AN. In other words, others 'expect' the suffering status of people with SE-AN. These findings made the subthemes significant, when viewed as a theoretical underpinning of the theoretical category of 'suffering, but not in silence'.

Then there is the assumption of the 'childlike approach', in co-operation with other theoretical findings, which was also seen in Amy's narrative, as she was constantly comparing incidents. This situation revealed a wish for a 'childlike' approach by her parents, and was intertwined with the 'strengthening of the AN'. Amy disclosed that she wished to be a child again, and that she had an urge to be taken care of by her parents (L73-75), although this also indicated the dependence she felt regarding the communication with her parents. The excerpt of Amy's interview below illustrates this assumption:

> *"At home, I ate everything that I could lay my hands on. So, that ended up in big fights with my parents. And when I didn't binge, I wanted to eat nothing at all. That also yields tension and fights. Once, I was home alone, because my parents were on a holiday, I've received some money for daily groceries but I only bought binge food for it. All day through I was eating and vomiting."*
>
> (Amy: L48)

And later, Amy explained her struggle to be noticed:

> *"We moved to another house, we changed into a blended family with seven family members who were not my real family, we moved to another city where I didn't have any connection with other people at all. And I really didn't want to move away. However, I had to start at a new school, my parents were divorced and they were always fighting with each other. I think it was just everything together. I think, I searched for some control in eating and it gave me some security"*
>
> (Amy: L58)

A few sentences later, Amy elaborated on a situation where she felt rejected by her family, and she tells how she reacted to this situation:

> *"I wasn't allowed to stay at my mom's house, and if it happened anyway, he (father) blamed my mom for that. And later, once when we lived with the blended family, my mom said: We want to have some peace, so, for me that was a forced signal to go to my father again.*
> *I: Did you bring an imbalance within the situation?*
> *A: My eating disorder for sure, and my step father, I consider him as my real father, his children were at home for once every two weeks, he arranged other parenting rules with his former wife, so my mom and he wanted to have some rest with the three of them, with my newborn baby brother. So, that situation obligated me to go to my biological father at the weekends. But when I went to my dad, it was hell. I bought all the food and ate it all, and that was my technique to survive those weekends".*
>
> (Amy: L73-75)

The quotation (L73-75) from Amy identified her sense of rejection. Her ED functioned as a mode of communication to seek to the attention of others. This elicited reactions from others, although her parents established limitations to some of her behaviours, so that the opposite occurred, and she was thus separated from one parent (her mother). As a result, Amy felt further rejection and, therefore, her sense of suffering was greater. Due to the supportive knowledge of my personal construct in relation to the therapeutic contacts I had with Amy, which had been gained by my observations at the SEDU, this gave me an insight into how she believed she had to act in contact with professionals. To strengthen this idea, I revisited the focused codings in the search for comparative data in the further exploration of the property. According to Amy's narrative, the theme of the comforting feeling of 'staying childlike' was noted and, a strong correlation with rejection was suggested. It was useful to gauge the narrative by means of the memo writing, which revealed new insights according to the 'rejection' theme. Memo 5 is given below.

Memo 5: Exploring the property of staying childlike in the narrative of Amy

In the therapeutic contact I had with Amy, I noticed subtle changes in contacts she had with staff members, family, and her boyfriend. The tone of her voice sounded more childlike, sometimes nagging, and she often cried at times the staff attempted to discuss eating disorder behaviours. At such moments, Amy clearly stated that she was not in charge of being able to adjust her behaviour, thus, the appeal on the mature responsibility in accordance with her age did not succeed. Then, in therapeutic family contact, it was striking how the eating disorder 'ruled' the communication with her relatives.

This is in accordance with the former patterns in her youth. Amy did not agreed with the parenting rules both parents stated; contact with her father on a regular basis was experienced as a punishment, and, Amy felt out of place as a family member in the 'new family' her mother created. For Amy, the exposure of suffering through the eating disorder was an effective way of being noticed, to the extent that the family maintained a 'distance' from the AN by parenting rules and issues. In constant comparison to Amy's interview, the experience of Amy's inability to take a mature position was revealed. With this, inserting the theoretical finding of 'staying childlike' is highly significant as an underpinning for the main category, 'suffering, but not in silence'.

In conclusion, in the dimension of the theoretical coding of 'staying childlike', rejection turned out to be a key factor, whereby the disclosure of the property of 'suffering, but not in silence' is supported. Furthermore, it indicated the following theoretical findings:

Staying childlike
The eating disorder says it non-verbally
Other people's constructs according to staying childlike

Memo 5: Analysis of data set of Amy

In the memo above, I presented the insight into my thinking process during the data analysis and the explorations of the findings. The memo suggested the assumption that Amy felt disregarded by her family, which, in turn, triggered her into producing disturbed eating behaviours. The initial codes, 'fighting with father' and 'losing the support of parents', made the data grounded. The disclosure of the theoretical finding of 'staying childlike' also revealed another closely-related theoretical finding, that the eating disorder ‘says it non-verbally’. These findings increase the feelings of rejection that she experienced. The ‘non-verbal communication’ suggests a passive aggressive communication form, which is closely-related to Amy’s behaviour in reaction to her contacts with the healthcare professionals and other important people who are involved. Furthermore, the memo contributed an insight into the theoretical finding of ‘other people’s constructions’, with regards to Amy’s construct of her parents’ behaviour (L73-75). The theoretical coding is underpinned by the initial coding of ‘keeping away the eating disorder from the family’ and ‘keeping the family at a distance’, which made the findings grounded.

While focusing on the core findings of the property, such as ‘childlike behaviour’ and ‘the social position within SE-AN women’, in the search for an explanation of this behaviour, as revealed in the constructs, the constant comparison of data revealed the following three concepts, which directs the study towards a higher level of theoretical momentum. These three concepts are:
1) ‘the avoidance of rejection and responsibilities’ (Amy: L73-75);
2) ‘the request for care’ (Mariah: L76-78; Amy: L48; 58; 73-75); and
3) ‘the disagreement of the childlike status’ (Violet: L41, L111; Sarah: L33, L66).

Thus, the findings underpin the confirmation, and conversely, the non-confirmation of a childlike approach. Regarding the concept of ‘staying childlike’, a certain degree of dependence is needed, which is grounded in the data. Therefore, dependence, and thus, the adaptation of the childlike approach in the SE-AN status, is suggested. The illustration below suggests a cycle of adaptation.

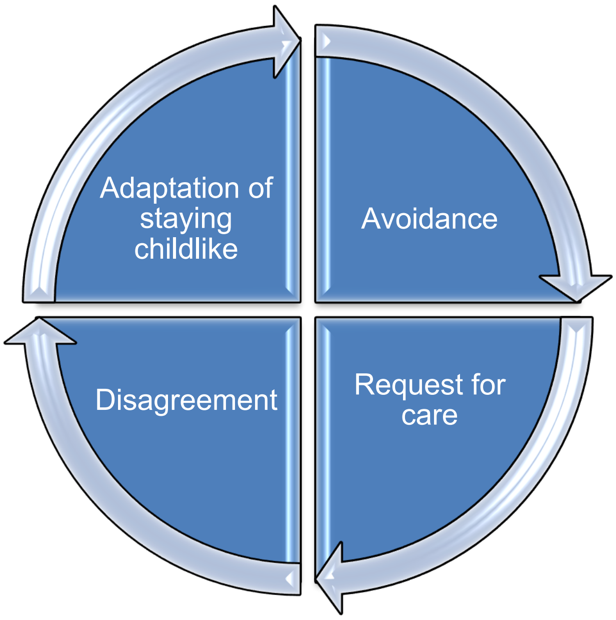


Figure 7.8: Cycle of adaptation of the ‘staying childlike’ situation

In the figure above, the continual, surrounding, light blue arrow suggests adaptation, and it encloses the three concepts as developed in the exploration of the property of ‘I will always be the girl with the eating disorder’. The three concepts together are responsible for the childlike behaviour and the need to maintain certain behaviours within the women SE-AN sufferers.

In conclusion, the ‘I will always be the girl with the eating disorder’ property revealed the dimension of staying childlike, and is twofold. Firstly, it indicates ‘adaptation & dependence’ of the SE-AN status, and secondly, it functions as a primary defence against rejection. Through this behaviour, the phenomenon of ‘not taken seriously’ emerged, which underpins a childlike approach through others in the constructs of the women with SE-AN. Consequently, exhibiting childlike behaviour, as seen in the SE-AN sufferers, greatly appeals to the morals of the other people involved, and this affects the mutual understanding. In this way, the initial codings, as found in the constructs, made the data grounded. Thus, constructivism disclosed an in-depth understanding of this phenomenon. With this, I consider ‘staying childlike’ in the women with SE-AN as a fresh and innovative finding. In general, the property affects the QoL of the women with SE-AN, and a diminishing QoL is suggested.

7.5.2 The second property: ‘being seen as a psychiatric patient’

The analysis of the first property directed my insight towards the second related property, the experience of ‘being seen as a psychiatric patient’. With reference to the initial coding diagram[43], the women claim that the major influences on their SE-AN condition is the psychological and physical functioning, in terms of *‘how’* they are approached by society, and consequently, *‘how’* the women approach themselves, as seen through the lens of a psychiatric diagnosis. With regards to the literature (van Weeghel et al., 2016), cultural aspects, as developed in Western countries, contribute to a more general disapproval of a psychiatric diagnosis, which is recognisable for AN patients, and current study findings referring to specific opinions were grounded in the narratives of the SE-AN sufferers. In the exploration of the narratives, multiple initial codings were found related to the experience of stigma and being mentally ill. Both concepts were twofold, whereby themes appeared in other people’s constructions as well as their own beliefs in how they experienced their personal situation.

Furthermore, in the interviews, the women participants used relevant terms, such as ‘craziness’, with the term appearing to be representative of the phenomenon referred to as ‘being mental’. Likewise, it revealed the phenomenon as seen through the eyes of other people, and which also carried a stigma with it. The women’s quotations below emphasised the empirical findings regarding the phenomena of madness and stigma as an underpinning of the ‘suffering’ category:

> ***“I am not normal, I do things which aren’t healthy, I walk like a fool, that’s why I think I don’t have the right to talk about it. I am not a holy person”.***
>
> (Mariah: L221)

Then, later in the interview, the subject of craziness is repeated:

---

[43] Figure 6: Diagramming initial codings.

> *I: "Do you think you are crazy?*
> *M: Yes, crazy according to eating, yes, yes.*
> *I: Oh, that's important.*
> *M: I wonder if I'm going to go crazy because it becomes worse.*
> *I: Exactly, it becomes crazier, more bizarre?*
> *M: It's going to be more crazy, more bizarre, worse and not better."*

(Mariah: L230-235)

Mabel agrees and makes three references to the topic of 'craziness':

> *"Maybe I'm really crazy, that is also what they say. However, I try not to think about that too long."*

(Mabel: L53)

> *"I have to do things at home, like cleaning and exercising, it's like, constantly being active, be firm, never allow myself to take some rest, even if I am so tired. And finally, I allow myself to eat something".*

(Mabel: L38)

> *"I try to find affirmation, like, that I'm not that crazy at all, otherwise, it ends up in less eating as a punishment. I have to punish myself by obsessive exercising and cleaning."*

(Mabel: 55)

Sophie also referred to the topic as seen as the construct of her family:

> *"They treat me as a person with brain damage because of the anorexia."*

(Sophie: L66)

Later, Sophie discusses the stigmatic SE-AN position:

> *"I think there are lots of people, which you cannot recognise as eating disorder patients, they lead a normal life, more or less, but they seriously do suffer from eating problems. I personally think that we can offer more attention to those people. They always have to fight against all kinds of prejudices. I think it is a lost group. When I notice the attention for other people with a chronic condition, there are all kinds of organisations and supportive care, such as in work and social care. And according to people with a chronic eating disorder condition, there is not so much support and you will be rejected.*
> *I: Do you think that you belong to this specific group of people who live their lives but meanwhile there is suffering going on?*
> *S: Yes, definitely. I really suffer from the prejudices and the difficulties of the disease. I feel ashamed about myself, about my condition".*

(Sophie: L80-82)

During the initial coding process, it became apparent that several women made references to 'craziness and stigma'. Mariah and Mabel's narratives referred to the actual term 'crazy' (Mariah: L233; Mabel: L53, L55). Both interviewees related their craziness to the eating disorder's thoughts and habits, which strongly influenced their lives. According to Mabel, she adapted the range of people within her social environment, which also influenced her view on 'her craziness'. For her, the constructs made by others seemed to be adapted and turned out to be a 'belief' (L53); but if Mabel refused to adapt to the construct, she expected a certain punishment (from herself). Therefore, with this insight, it made sense for Mabel to accept the construct of 'being mentally ill', in order to avoid punishment. Furthermore, the initial codings, such as 'defining craziness', 'craziness is growing', 'earning food' and 'punishing myself by not eating', underpinned the theoretical code which made the data significant. Mariah's view then referred to stigma (L230-235), and it became apparent that she was seeing herself 'through the lens' of her social environment. Mariah clearly stated that her behaviour was 'insane', and she connected this insanity with her eating manners and thoughts, but also with her daily experiences of how she dealt with it. With this, Mariah adopted a stigma and placed herself outside the social world. Thus, Mariah answered to the constructs of others by adopting a stigma. In reference to Sophie's construct (L66), she used the more rigid term, 'somebody with brain damage', which emerged in family contacts. With this comment, Sophie was resentful, as her family did not treat her as a responsible human being. Sophie clearly suffered from the way her family and the societal environment approached her. Furthermore, Sophie referred to suffering from the prejudgement of others, and the shame she experienced in relation to her family, which brought about her disturbed eating behaviour (L80-81). Conversely, Sandy's excerpt, as given below, referred to the acceptance of the label of a mental illness and a stigma (L122-131). In the excerpt from Sandy, she accepted her 'state of being mentally ill'. For Sandy, the condition of being mentally ill worked as a protector against the social pressure and the expectations she imposed on herself. Together, these findings made the theoretical finding of 'self-stigma' significant. The initial codings of 'defining an excuse to take it easy' and 'living in a mirage' underpinned the findings. Moreover, by adopting a mental illness, the women with SE-AN experienced protection against social pressure. This indirectly responds to the unrealistic pressure which society puts on people. Incident-to-incident coding brought me to this insight. Sandy supported the acceptance of the diagnosis, and the excerpt below began with a question that I asked her, Sandy uses a 'train' as a metaphor which represents the life with which passes by and in which others in her life also participate:

> *I: "How is your life influenced by anorexia?*
> *S: I used to have great plans, I studied, and worked, I was in the train were everybody took place. That's what I wanted. So I have done those things and finally, I couldn't hold on to it, I graduated, married, a house, mortgage, social life, sports, parties, I've done everything. But, like always, it was too much. I didn't show myself, my personal needs did not matter. I was doing the things everybody did.*
> *I: You were doing the things everybody did, and you felt, uuuuhm, you felt forced to take part in it?*
> *S: At first I wasn't forced because, like everybody, I was on that train, because it is the picture, made by my parents, by the world, Facebook, you know, I don't know, you'll be a part of it. You are not really connected, it wasn't my personal need at all.*
> *S: And I figured that out the first time, and that was really shocking. By the time I was pregnant... I worked... The picture was complete, then I thought: Oh, I don't have to work that much anymore. Then I became more and more ill... It was more like, now I can say to the world, 'Enough!'*
> *I: Because you had a reason?*
> *S: The ultimate reason, then nobody can say that I'm weak or lazy... Yeah. I'm ill".*
> (Sandy: L122-131)

The excerpt above demonstrated the acceptance of the SE-AN condition, and thus, the acceptance of a psychiatric illness. Furthermore, the excerpt is closely-related to the self-stigma in Sandy's construct, as it served to provide a protective factor against social pressures, with respect to the theoretical category. Sandy's non-verbal behaviour justified her choice, as Sandy clearly suffered, and her behaviour underpinned her choice *not* to suffer in silence. Finally, in her construct, Sandy said it verbally to the world:

> *"Enough!"*
> (L129)

‘Meeting expectations of others’ and ‘denying my personal needs’ functioned as important initial codings, which made the data grounded and thus, empirical. Moreover, in the context, in speaking the words *“It’s enough!”*, this functioned as an ‘in vivo’ code, as it appeared as a ‘guide’ to indicate the importance of data (Charmaz, 2006).

In conclusion, by scrutinizing the data of the theoretical category of ’being seen as a psychiatric patient’, the status, and thus, the influences of a mental illness, the stigma and the impact of the phenomena on the women SE-AN sufferers, emerged. In the processing of the theoretical momentum, consistent comparative analysis was used. The existence of the stigma related to mental illness indicated a strong impact on the quality of life within the women with SE-AN. In general, I considered the property that emerged as a significant finding and it was one that provided a deeper understanding, in terms of the phenomenon of the experience of ‘being seen as a psychiatric patient’.

7.5.3 The third property: ‘self-image’

The analysis of the previous property directed my insight into the next closely-related third property of ‘self-image’. Two women were very explicit on this topic in their interviews and explained the AN influences on their personalities. In an attempt to stay in close proximity to the theoretical category of ‘suffering, but not in silence’, I decided to search for the influences of SE-AN on the personality, in the sense that ‘suffering’ is indicated. The following findings revealed the involvement with the previous property of self-stigma and self-image. The following excerpts suggested the connection between these properties, beginning with Sophie, who clearly stated the influence her AN had on her identity:

> *“I think that I’ve lost a part of my identity as a person, as Sophie, the eating disorder took a part of my identity, I do things I don’t want to do but I have to. I make choices but they aren’t mine. It’s like something is stolen from me, it feels like they took it away from me.”*
>
> (Sophie: L31)

Later in the interview, Sophie referred to the topic again:

> *"It's so much a way of hurting myself; you do things in order to hurt yourself, underpinned with all kinds of thoughts.*
> *I: What do you mean by that?*
> *S: Why I hurt myself? So, I won't be able to feel emotions. I don't have to deal with anxiety, fear, hurt. It helps me to avoid those feelings. But also, I won't be rejected. Because of my eating disorder, I experience the feeling of control".*
>
> (Sophie: L106-109)

In Sandy's construct, her concept of 'self' appeared in the shape of a negative self-experience:

> *Regarding yesterday, it was the birthday of my friend's daughter, I promised to visit them, but I felt so ugly and, with the large amount of people at that party.... Then I end up with; I've promised to visit you, and I still would like to do that, but I will see you next week for a coffee. I didn't say: simply, I do not want to be in the group with my ugly body."*
>
> (Sandy: L208)

An exploration of the previous excerpts clarified and explained the 'loss of identity' and the 'coping with emotions'. In the case of the excerpt from Sophie (L31), she felt compelled by the eating disorder to perform certain behaviours. In her construct, the eating disorder can be considered as an external force. Moreover, it is a part of her identity that has been stolen from her. Initial codings, such as 'losing my personality', 'not managing my time' and 'personalising the eating disorder', underpinned the data in the property of self-image, which made the findings grounded. Conversely, Sophie clearly stated the choice she made to maintain the eating disorder, whereby she continued contributing to the stigma as it reduced the impact of her emotions (L106-109). Initial codings, such as 'defining the feeling of control' and 'defining peace because of the eating disorder', made the property of self-image significant. With regards to Sandy's excerpt, it demonstrated an 'in vivo' code (L208):

> *"I don't want to be in the group with my ugly body".*
>
> (Sandy: L208)

Sandy's statement addresses the involvement of self-image, stigma and the impact of the Anorexia on her thinking strategies, whereby the strengthening of a negative self-image is observed.

With regards to the narratives, it was highly relevant to give attention to the phenomenon of 'identity in AN' in the interaction with suffering. According to the narratives, the women were aware that their AN strongly influenced their self-image and provoked the development of a negativity, although SE-AN mitigated emotions in cases where the women were able to deal with them. To gain a better understanding of this aspect, I decided to write a memo (6) of my thinking strategy regarding this topic.

Memo 6: Exploring self image

Although identity turned out to be a major finding in the context of SE-AN participants, knowledge according to this topic is already there (Nunn, 2009). Phenomenological and interpersonal aspects are prominent in the clinical presentation and interactions (Amianto et al., 2016) which are likely responsible for disconnection with emotions and also to body sensations. A developed theory of the AN identity supports the influences of the AN on the personality (Williams et al., 2015). The theory advocates the separation of the self from the AN and the acceptance of fear of the unknown.

In my project, I administer to contribute to a deeper understanding of the relationship between the 'self image' and 'suffering'. And it appeared that participants seem to give the AN permission to trade places with their 'self' in order to support them in dealing with emotions. Through the lens of 'suffering'; SE-AN participants suffer from their negative self –image. With this, constructs refer to negative influences of the AN on their behaviour, such as avoiding social situations and obeying a dominant leader (the AN) by doing things that they do not want to do. On the other side; the on-going suffering status protects them against painful emotions, which implicates the acceptance of suffering. In conclusion, the SE-AN status contributes to a negative self image which is experienced as suffering, nevertheless, acceptance of suffering functions as a protective factor in the coping with emotions. Thus, the SE-AN status indicates the acceptance of a negative self image in the protection against threatening emotions and thus, the suffering is an on-going process.

Memo 6: Exploring the dimension of self-image of women SE-AN sufferers

The memo above served as a 'guide' in order to avoid getting lost in the subject of 'self-image', bearing in mind that knowledge relating to topics, such as, 'the AN identity' and 'influences on the personality through AN', already exists, and will be further elaborated on in the discussion chapter (Section 11.2: Discussing the core category: Suffering, but not in silence). Furthermore, this also helped gain an insight into the relationship between the continual suffering that the women SE-AN patients experienced and the personification of the SE-AN condition indicated as ‘acceptance’. This coping style supported the women in dealing with their emotions, and thus, powerful influences on the personalities of the women with SE-AN women are indicated, such as a negative ‘self-image’ and ‘control’. In addition, changes in ‘self-image’ contributed to other people’s constructs regarding stigma. As a result, the initial codings functioned as the underpinning of the theoretical finding ‘self-image’, which made the data grounded. Finally, the codings were supportive in the refining and the limitations of the dimension of the property.

In conclusion, an exploration of the property clarified the SE-AN influences on the ‘self-image’, with regards to the partial loss of the ‘self-image’, which are indicated by the personification of the AN. With this, the women with SE-AN experienced feelings of control, which was generated through the AN. Hence, it is suggested that the partial loss of self-image functions as a protector against painful emotions. In general, I considered the findings which refer to the SE-AN influences on self-image as significant, and being worthy to answer the research question of this project. These findings, therefore, indicated a negative influence on the experienced quality of life within the women SE-AN sufferers.

7.5.4 The fourth property: ‘addiction’

As the next dimension in building on a robust theory of the main category of ‘suffering, but not in silence’, I presented the elaboration of the property of ‘addiction’. This property interfered with the previous property (‘self-image’) with regards to the impact that addictive eating disorder behaviour had in respect of the constructs of the women with SE-AN. Furthermore, the property ‘addiction’ is framed in the ‘consequences’ due to the axial coding (Figure 7.4). Data related to the property of addiction was scrutinised, starting with an excerpt from Sandy, one of the women who clearly recognised addictive behaviour in herself, even proposing the word ‘slave’ in her construct (L181):

> *“I: When was your eating disorder the strongest and how did it affect you?*

> *S: Yeah, that's when I wanted to die…I was a slave, I wasn't in charge anymore, didn't dare to stand up, was afraid of everything. I was so tired, when I get out of my bed, the only thing I did was give attention to my eating disorder habits. I had to eat, vomit, eat, vomit, that's how my days passed.*
>
> *I: Yeah.*
>
> *S: I ought to have been happy when I arrived in my bed at night. Always hoping that the next day will be better. But it wasn't."*
>
> (Sandy: L180-183)

Later in the interview, Sandy's construct referred directly to her addiction and her tendency to reach for substances and therapy:

> *"I see my eating disorder as an addiction, like everybody has an addiction. And my tendency to dependence, pills and therapy is often too big. We all want to be strong. All the people with eating disorders want to be strong. And I am scared, always, even of myself. How I long to take that pill. Just once. Uuuuhm. Therefore I have to choose, I take another sleeping pill, I sleep in a while or I lay down and puzzle the whole night. That's life, huh."*
>
> (Sandy: L322)

Similarly, Sophie experienced the obligatory exercise as an addiction:

> *"If I take a look at my urge to do physical exercise, I really don't want to act that way, and the thoughts about eating, the rules, and the restrictions. It's not what I am. Moreover, it's the opposite of what I am. That and all the time I have to put into my eating disorder, so I won't be able to do things anymore I really like to do. I haven't got the time and the energy left. So, I became somebody and the current life I live isn't what I really want, how I really am. So, it's not that I'm completely faded away, but I think half of me is gone, or at least, my life has been taken over. It's not really gone, I noticed it, for example, when I make a decision to skip some nutrients, I often think, I really want to eat this or that, or, if I was completely me, I would have eaten it or, I didn't go for that walk because I'm very tired. So, I notice, when I make decisions regulated by my eating disorder, I'm conscious of what I do and who I am and how I act. It's still there but I can't accept it as what I want. So, I think, it's taken over me."*
>
> (Sophie: L33)

A few sentences later Sophie illustrated her dependence on the AN:

> *"Meanwhile it brings me control. Because, if I don't follow the rules I feel panic, fear or I feel lousy or bad. Uuuuhm, guilt, uuuuhm, dirt, like, for example, I ate something that I shouldn't have done. It's so much a mixed feeling, on one hand, if I admit it, there's irritation but it also gives me peace. That's what it gives me. The feeling of agitation, given by the fact that I've listened to myself, is worse than the feeling of, uuuhm, how shall I say it? The eating disorder is more bearable and important than the alarm bells when you don't listen to it. The feeling that comes over me once I don't commit to the eating disorder, is simply too heavy for me. So I always surrender."*
>
> (Sophie: L41)

Sandy (L180-183; L322) clearly felt that the AN was an addiction experience, to the extent that she literally referred to the phenomenon as an addiction. The following initial codings, 'lurking eating disorder' and 'seeing my eating disorder as an addiction', made the findings significant and thus, the data grounded. Conversely, Sandy attempted to diminish the phenomenon of 'addiction' by comparing her personal situation of addictive behaviour to that of healthy people. To get a better understanding of this construct, I have worked on the theme in a memo (see Memo 7 below):

Memo 7: Exploring the addiction experience, defining the properties

Addiction to the eating disorder is often defined as 'craving' in the context of binging and purging; this behaviour in the context of the narrative of Sandy is explored as binging and vomiting during several hours. In binging, large amounts of food will be eaten; the urge to purge is in potential just as strong as the binging part. Both must take place otherwise, there will be no relief experienced. The sum of this process is exhausting and it happens that the patient damages herself. Sandy identifies this as addictive behaviour, and for her, it is corresponding to phenomenon of craving. The term craving is often used in the addictive healthcare as it becomes to substance abuse. Sandy and I discussed this certain behaviour several times. Mostly, the discussions were difficult, it was affected by the feelings of shame and self hate. Another factor was that the craving seems to be the insurmountable factor of 'not' using the in-patient setting temporally. During her stay, Sandy knew that she could not commit to the craving, after all, she did not want to lose the faith she experienced at the SEDU. Then, Sandy considered her home as 'infected' regarding the addictive behaviour. For her, that was the place were she experienced those harmful episodes.

This phenomenon, and how it occurred within Sandy is for certainty not a general symptom as seen in all ED patients. Concerning the duration and the course of the Sandy's eating disorder, there is a seemingly relationship with the duration of the illness and the existence and intensity of the 'addiction type' behaviours. In conclusion, the phenomenon of addiction in severe eating disorder habits can be provoked by its duration, the type, and intensity of the eating disorder, and is framed by intense self hate.

Memo 7: Exploring the addiction experience, defining the properties

The memo above provided an insight into the differences between *how* addictive behaviour in

AN is experienced and *how* addictive behaviour can be seen as a punishment in respect of the intense self-hate that people with SE-AN experience.

Regarding the narratives of Sophie (L31-33), she experienced her addiction due to extreme exercise and restrictive eating behaviour. In her narrative, Sophie stated that the related addictive behaviours became stronger as the AN condition continued (L31-33). As a result of this, she claimed a high level of suffering through her addictive behaviour. The initial codings of ‘empowering the eating disorder’, ‘the eating disorder is taking all my energy’ and ‘the eating disorder never stops’ strengthened the theoretical coding. Nevertheless, Sophie’s narrative is not directly related to the previous forms of ‘craving behaviour’ which were described, such as vomiting and binge eating. Sophie also experienced a strong addiction to her AN through exercise (L41). On one occasion, Sophie refused to obey the ED ‘rules’, and she experienced feelings of disgust and anger, which indicate an intense dependence. In coping with certain overwhelming emotions, ‘adaptation’ of the situation seemed necessary, referring to a pronunciation in Sophie’s excerpt (L 41): *“The eating disorder is more bearable and important than the alarm bells when you don’t listen to it.”*

To strengthen the findings, I framed ‘addiction’ by using the technique of axial coding. Therefore I used theoretical codes which interface with the other main categories. The following figure (7.10) illustrates the connection between the properties of addiction and the other findings within the main category.

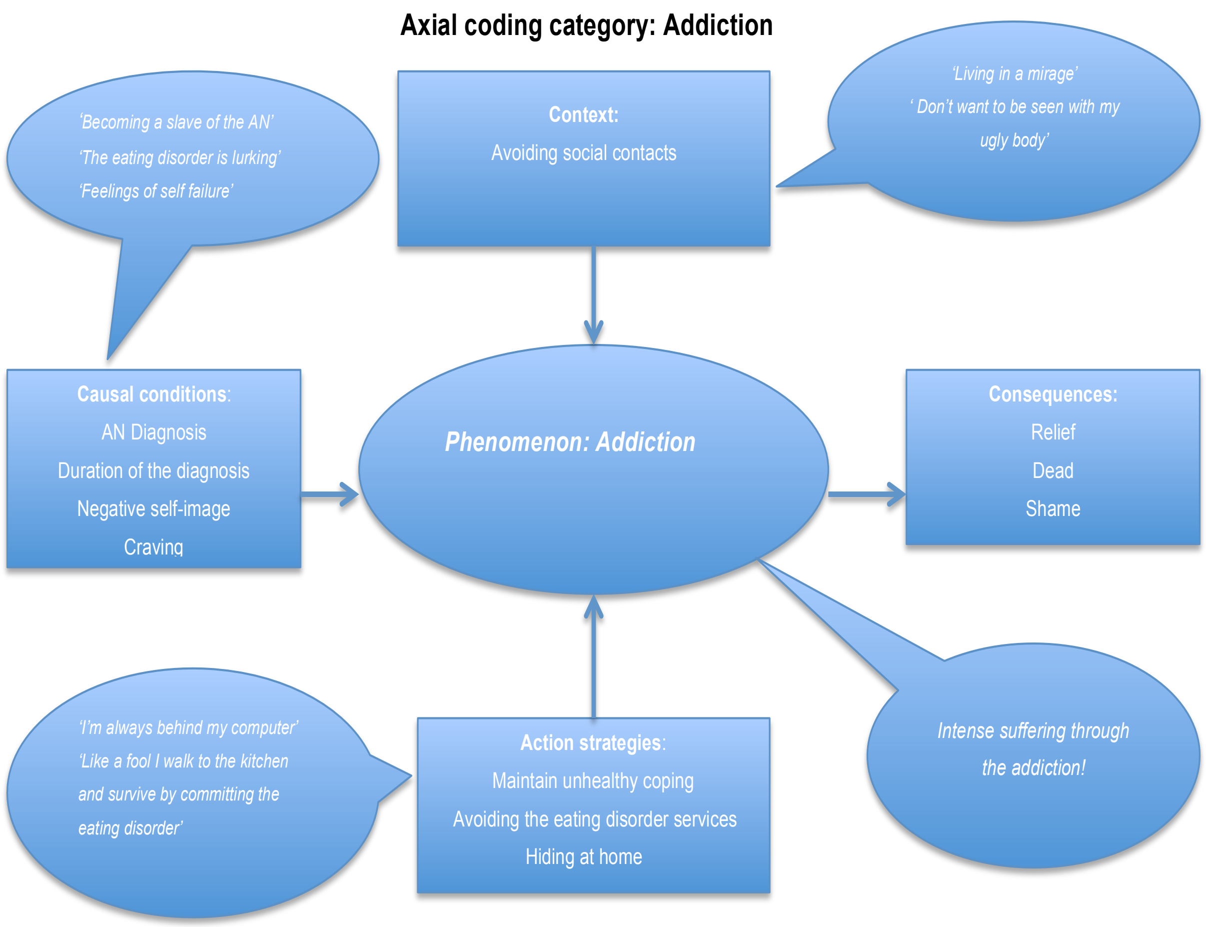


Figure 7.9: Axial coding of addiction

The method of axial coding provided an insight into the dimension of the property which is suggested in the following concepts: conditions, consequences, action strategies and the context. In all dimensions, 'addiction' indicated intense suffering. Next, text balloons were added, which contained the women's constructs, and thus, this directly supports the dimensions.

One memo explores the addictive behaviour of people with SE-AN, and this demonstrates the significance of the finding (see Memo 8):

Memo 8: exploring addictive behaviour in SE-AN

In the exploration of addictive behaviour I refer to several patients with a specific request for help to overcome strong addictive behaviour, which has its roots in eating disorder habits. In general, these patients experienced severe suffering from binging and purging behaviour, which seriously disrupted and influenced their lives. These patients were not included in this project but all of them suffered from an SE-AN condition. Furthermore, they experienced a total loss of control referring to eating, purging and thus their daily activities. In addition, one of the patients experienced a moment of complete desperation, she even asked the team as a last request to sew her jaws together as a solution against the intense binging she experienced. However, a surgical team of the adjacent general hospital rejected this for the following reason; they were not able to estimate the consequences of the intervention. Another imported issue is the ‘crime scene’; all of the patients described their houses as ‘infected’ referring to the intense eating and vomiting they experienced. Besides their ‘cry for help’ the SEDU was not able to support the patients by a definitive break through of certain behaviour in terms of extinction, however, some managed to reduce the frequency and intensity of the experience.

With this, in my perspective is addictive behaviour a significant finding amongst people with SE-AN and influences of the QoL effectively.

Memo 8: Exploring addictive behaviour in SE-AN

In conclusion, framing the property of ‘addiction’ into the context of the theoretical category of ‘suffering, but not in silence’ demonstrated significant suffering, and thus, the request for taking the SE-AN condition seriously through the emergent suffering by the operationalisation of the addictive effects within the SE-AN sufferers. As a result of this, the property of ‘addiction’ provides a strong underpinning of the theoretical category and presumes a diminished QoL within the women who suffer with SE-AN.

7.6 Summary

This chapter has presented the findings from the main category of ‘suffering, but not in silence’. A construction of the four properties, supported by the outcomes of the analysis, made this main category significant. The study findings highlighted that people with SE-AN engage with their social world through complex psychological processes, whereby they interpret and give meaning to interactions. In general, scrutinising the study’s findings revealed that ‘staying childlike‘ and ‘being seen as a psychiatric patient’ produced negative influences on ‘self-image’, and finally, it suggested ‘addictive behaviour’. In this chapter, I have presented the four properties, identifying how people with SE-AN interact, and how they construct behaviours to help them stay involved with their social world. Nevertheless, such behaviours are responsible for a diminishing quality of life as experienced through the women with SE-AN.

Firstly, the property of ‘I will always be the girl with the eating disorder’ was revealed. It identified how the women SE-AN sufferers made adjustments in order to avoid rejection, by adopting a childlike approach, and by demonstrating a dependence on their SE-AN condition. Moreover, certain behaviours are pivotal in the diminished quality of life experienced by the women SE-AN sufferers. The next category explored the themes which are related to the mental condition and to dealing with the stigma involved, which identified the concept of ‘being the psychiatric patient’. The women with SE-AN either considered themselves as mentally ill or the societal environment was responsible for judging them as being mentally ill. The property of ‘being the psychiatric patient’ embedded in the women a diminished quality of life with regards to its influence on their daily functioning. Thirdly, in exploring self-image, this contributed to the loss of the personality of the person living with the AN condition, along with the influences of the SE-AN condition itself on the patient. As a result of this, the development of self-hate and a negative self-image is strengthened, and the women participants identified the burden of such experiences. Thus, this property presented a strong negative influence on the quality of life, and an ongoing diminishing quality of life is also plausible, as influenced by the loss of personality. Finally, the fourth property represented is ‘addiction’. This property identified that SE-AN sufferers met certain psychological and physical influences, which were comparable with experiences as seen in substance abuse. In turn, this may cause a strengthening of, and thus dependency on, the SE-AN condition. As a result of the corresponding ‘addiction’ pathology, I concluded that ‘addiction’ is partly responsible for a diminished quality of life within the women participants.

This chapter has revealed the core finding of ‘suffering’ for those people with SE-AN, and all the properties together have led to the following conclusion. Together, the four properties identified how the interactions and the formed behaviours of the SE-AN patients allowed them to stay involved with their social world *through* their SE-AN condition. Thus, a diminished quality of life is indicated. Furthermore, the findings function as the communicator of the SE-AN status to society, and this finding appeared as responsible for a diminishing quality of life. In the next chapter, I elaborate on the main category of ‘one step forwards, one step backwards’ by defining its properties and dimensions.

Chapter 8 'One step forward, one step backwards'

8.1 Introduction

In this chapter, I present the category of 'One step forward, one step backwards', which considers the properties of *'Innocence'* and *'Guilt & Shame versus Recovery & Success'.* The properties are recognised through the elaboration and exploration of the initial findings, which underpin the theoretical significance of the second category of 'one step forward, one step backwards'. In accordance with the previous chapter (Chapter 7), I used similar methods to reveal the relevant data, starting with the development of a messy mind map to define the properties of this main category. The methods used provided insights into the next steps, such as framing the properties and elaborating on the properties, by exploring the dimensions. Finally, a conclusion is presented, where all the fractured findings are brought back together to give a general insight into the main category. Hence, I start by elaborating on the theoretical findings supporting the main category.

8.2 'One step forward, one step backwards'

> *"Sometimes I seem to have found the solution, but 10 steps forward always seems to end up in 20 steps back."*
>
> (Sandy, January 2017)

In qualitative research, it is not unusual to refer to these expressions by the words that the women use (Charmaz, 2008b). This article by Charmaz (2008b) referred to the administering of the 'in vivo' codes as a title, and/or as a sub-title, which directly indicated the data and, in turn, made the findings more robust. With regards to the second theoretical category of the study, 'one step forward, one step backwards', this title directly referred to an earlier comment by Sandy and, in accordance with the supervisory team, it is an equivalent for the continual process which characterises this chronic condition.

In the exploration of the data during the focused coding and to frame the findings, the continual comparative analysis identified the properties and their dimensions in respect of ‘guilt & shame versus recovery & success’ and of ‘innocence’. All the theoretical findings are given and supported by the constructs of others and prompted by the women themselves. For example, the narratives referring to the topic of recovery revealed the dimension of the reciprocation of love from others that the women experience. Conversely, the dimension which I called ‘weight loss’ revealed shame, guilt, hidden behaviours and, in contrast, innocence. In order to process the theoretical momentum, the 3-day meeting of the supervisory team[44] was implemented.

In the exploration of the category, several techniques were used, amongst them, for example, the clustering of the codings, in the search for the theoretical development (see also Figure 6.6[45]).

Below, I present a messy mind map (Figure 8.1) of the category, as a first step in the development of the category. This model suggests and defines the connections between the properties of the main category.

---

[44] Chapter 7: Suffering, but not in silence. Section 7.3: A brief explanation of the purpose of the meeting is described

[45] Figure 6.6: Clustering the codings in the search for theoretical development.

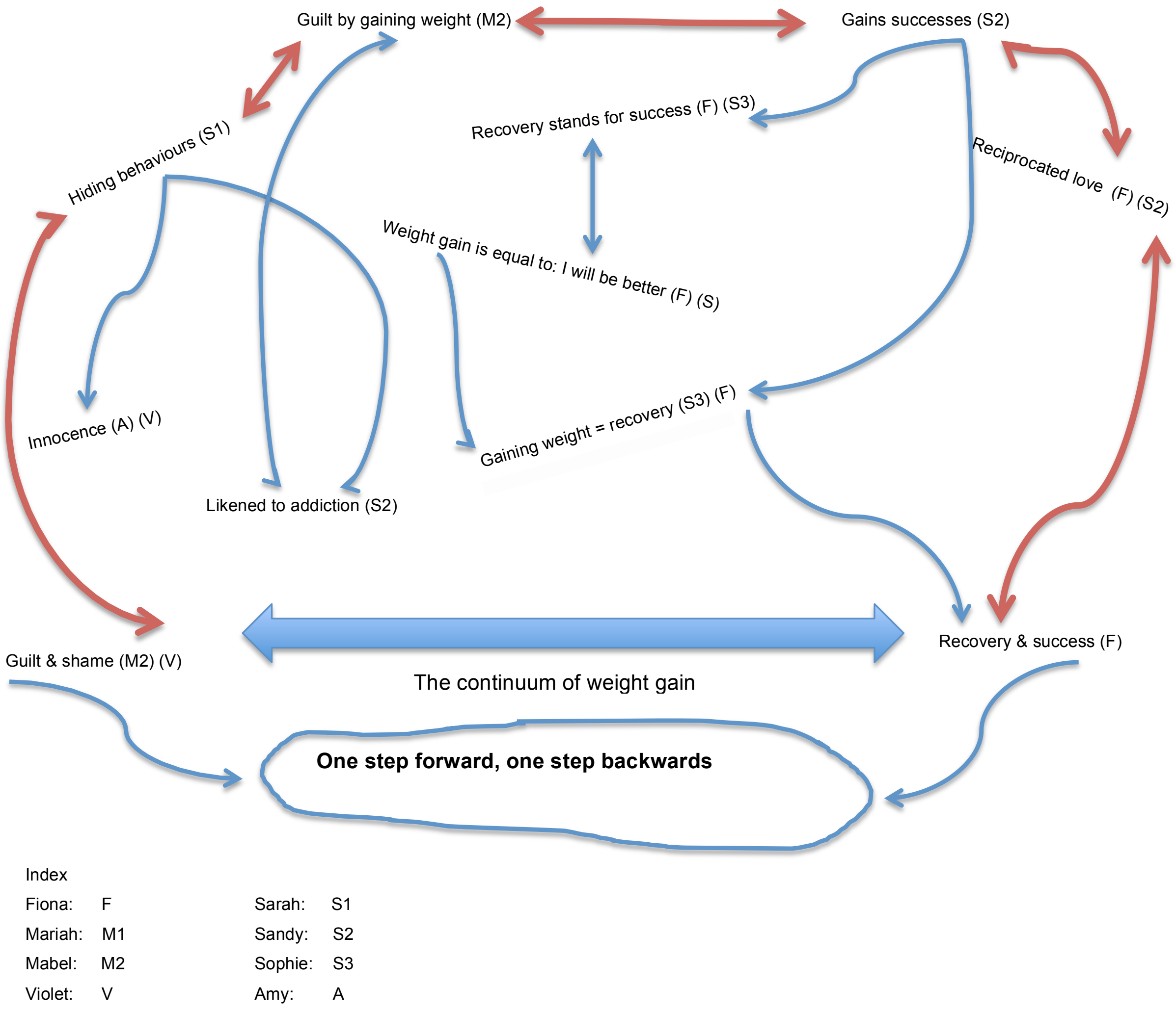


Figure 8.1: Messy mind map of the category ‘one step forward, one step backwards’

Figure 8.1 contains several theoretical codings, which are supportive of the main category, ‘one step forward, one step backwards’. The arrows suggest a connection between the theoretical findings. The initials beside the theoretical findings represent the pseudonyms given to the women (see the index in the figure). The theoretical findings indicate the empirical underpinning of the category by the women’s interview statements. The bold horizontal blue arrow at the bottom of the figure, which is supported by the red arrows, suggests a cycle with regards to the ‘continuum of weight’, whereby losing weight stands for certain feelings, such as ‘guilt and shame’, whereas gaining weight represents ‘recovery and success’. Finally, the developed theoretical category is encircled by a blue line. In accordance with the previous chapter (Chapter 7), I explored the coherence of the theoretical findings of the main category ‘one step forwards, one step backwards’, by using the axial coding technique (Figure 8.2). During the axial coding process, I turned back to the original data sets, and used the ‘search word function’ of the MAXQDA program searching for words such as ‘guilt’ and ‘shame’, and scrutinising the data in the search for contextual underpinnings referring to ‘guilt’, ‘shame’, ‘innocence’, ‘reciprocating love’ and ‘recovery and success’. To give a good insight into this process, in the axial coding diagram (Figure 8.2), I added some of the original words and phrases used by the women in support of the conditions, strategies and context within the axial coding paradigm. The axial coding was processed between the major analytical steps, in the middle of the analysis. By processing the axial coding, I have provided insight, and thus ‘meaning’ into the relationship of the short segments of texts with the larger parts of the text (Böhm, 2004).

According to the word usage of the women participants, most of them did not use words such as ‘recovery’ or ‘success’, except for Fiona. With regards to the text balloons in the figure below, in the illustration of word usage, I refer to Amy’s constructs, whereby she carefully avoids the subject of recovery in the context of her treatment and her responsibility for the results of it. Instead, Amy frequently repeated her treatment failure experiences. Typically, the women participants often used concealing language. An example is given underneath:

> *“I feel like a puppet, held up on strings, like I am tight up on the eating disorder. I would like to cut through the strings, so that I am able to determine my life. But, at the moment, the puppeteer holds all the strings tightly, he is in the lead. He determines my behaviour, and of course, I am in his power.”*
>
> (Amy: L102)

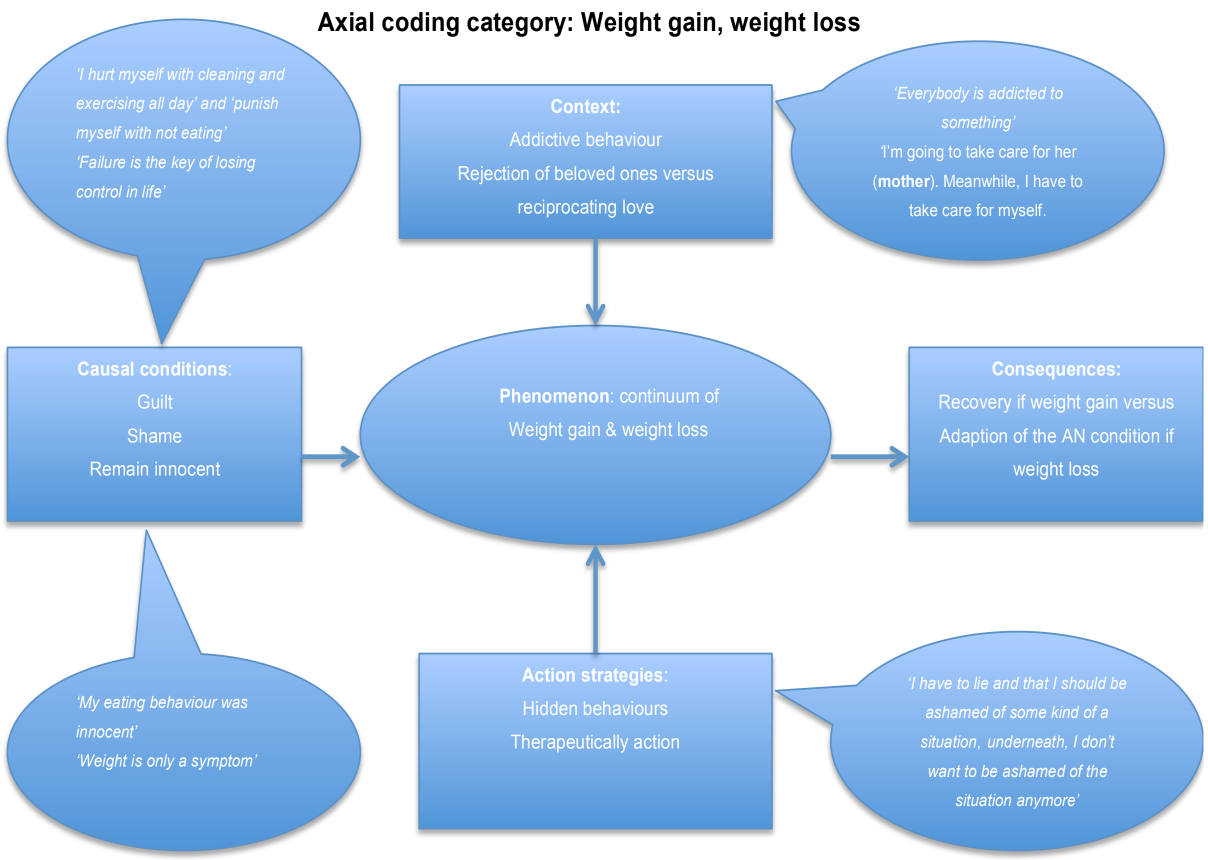


Figure 8.2: Axial coding of gaining weight & weight loss paradigm

In conclusion, the technique of axial coding was used to give an insight into the existing properties of the theoretical category 'one step forwards, one step backwards'. The findings underpin a strong relationship of the phenomenon of 'weight gain versus weight loss' and suggest an unbreakable cycle of 'success & recovery versus shame & guilt'. In the next section, I explain about the framing of the properties within the main category.

8.3 Framing the properties

As in the previous chapter (Chapter 7), in the framing of the properties, I used the coding family of Glaser (1978) to illustrate the theoretical findings, which belong to the main category of 'one step forwards, one step backwards'. Before processing the diagram and in order to gain an insight into which coding families appeared, I used the coding matrix (see Appendix 9.1). The overlap and the connections between the early findings were clarified during this coding process. Figure 8.3 below, explains these insights by using the coding family classification after Glaser (1978).

According to the main category of ‘one step forward, one step backwards’, the properties are explored in the following sections of this chapter. In Box 1 of Figure 8.3 below, I represent the first property of ‘innocence’. Box 2 identifies the strategy of ‘weight loss versus weight gain’, in relationship to the theoretical findings, such as ‘guilt & shame’ versus ‘recovery & success’. Both properties are underpinned by the influence of the theoretical findings, such as ‘weight gain is reciprocating love’, ‘other people’s constructs’, ‘hidden behaviours’ and finally, ‘acceptance of the label’. Regarding the rationales of the illustrated properties, I elaborate on a cyclic process, which suggests the delicate balance between weight gain and weight loss in the SE-AN patients. Thus, Figure 8.3 illustrates the relationship between the properties:

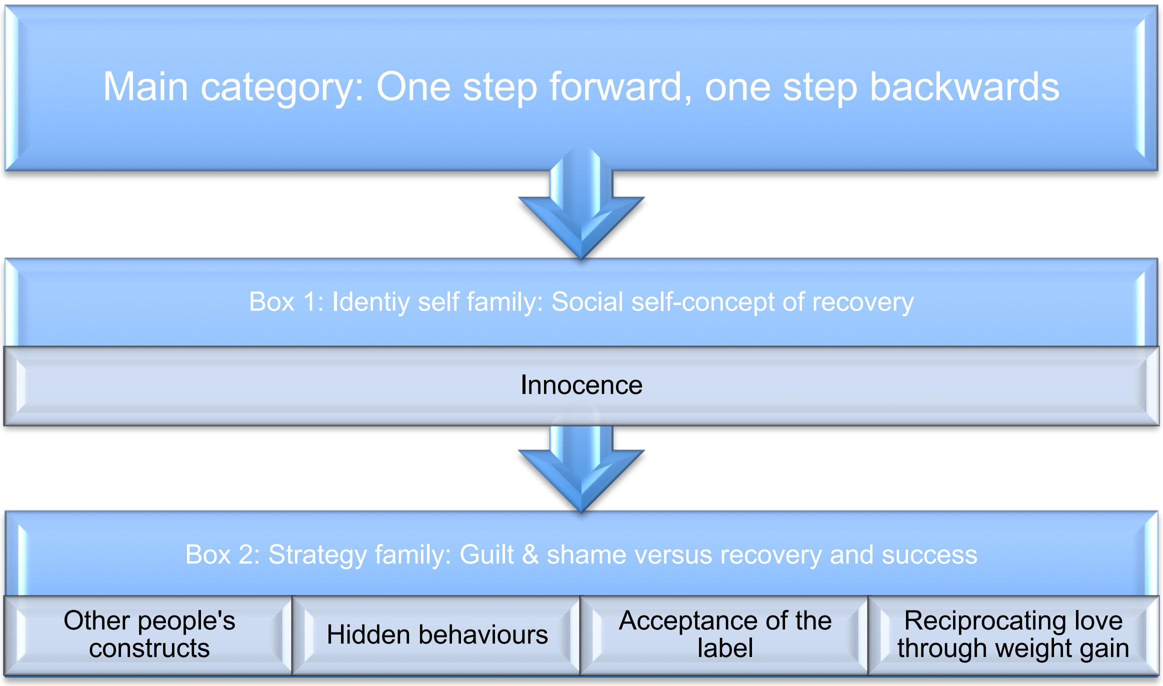


Figure 8.3: Diagramming properties within the coding family

8.4 Exploring properties and dimensions

8.4.1 The first property: Innocence

In this section, I present the first property of ‘innocence’, which belongs to the main category of ‘one step forward, one step backwards’. By scrutinising the interviews, comments were discovered which relate to this property. As a result of this, a strong relationship was observed between the previously-explored property, ‘I will always be the girl with the eating disorder’, as described in Chapter 7. To investigate whether there is a difference in the interpretation of both properties in the context of people with SE-AN, the data was carefully reviewed again. Referring to the interviews, the women participants did not explicitly use words such as ‘innocence’ or ‘childlike’ in the context of their behaviour.

The following excerpts from Amy referred to her childlike approach, which appeared in the constructs referring to family relations, especially those with her father. To achieve attention, Amy adopted the eating disorder in an attempt to be seen:

> *“I: So, I hear an accumulation of family problems and therefore you needed the eating disorder to get along with your feelings?*
> *A: Yes and that certainly counts for the situation with my dad, he neglected me, when I was with him, my eating disorder was all-over the place, in an attempt to handle myself in that situation. I couldn’t handle the fact how he was treating me.”*
> (Amy: L64- 65)

Then, later in the interview, Amy referred to a poem she wrote, where she describes metaphorically that she was not able to change her situation. In her construct, the ‘puppeteer’, which is her personal metaphor for her Anorexia Nervosa, is very strong and is in charge:

> *“A: If I remember it well, and the puppeteer, he rules the play.*
> *I: He directs everything?*
> *A: Yes, he takes care of the tragedy and he also ties up my family and loved ones, he forces them to watch the play about my life, completely powerless.”*
> (Amy: L112-114)

Referring to the above statement, Amy distanced herself from the responsibility of living an adult life. Alternatively, Mariah made the following statement:

> *"For example, sometimes, somebody eats a grilled cheese sandwich, that crumbles, and all the crumbs are beside the plate and every time, the nurse has to say: please, eat your crumbs. And then I said to the person: do you know what you can do? You can slice your sandwich into four pieces and eat it with your hands, less crumbling, then they say: "oh yeah, that sounds like a good idea, I will do that next time" but the next time, they do it precisely the same way and again, the nurse has to say the same things. I sometimes have the idea like it is kindergarten over here."*
>
> (Mariah: L215)

The exploration of these excerpts in order to process a subsequent theoretical momentum helped gain an insight into the concept of 'innocence'. Initially, in Amy's construct (L64-65), the ED was used as a powerful tool to get the attention of her father. The construct (L73-75) (property: 'I will always be the girl with the eating disorder') elaborated on her struggle to be accepted into a complex family. However, the childlike attitude she adopted, resulted in a greater distance between her and her relatives, which strengthened her fear of rejection by her relatives. In an attempt to stay in contact with her family, Amy assumed an innocent position (L112-114) by metaphorically blaming the puppeteer. Furthermore, deploying 'innocence' was provoked by her thin appearance, which Amy successfully pursued. This suggested the adaptation of her SE-AN condition. 'Adapting dependence of the AN', 'experiencing innocence' and 'the ED is a puppeteer' are the initial codings which made the data grounded.

Mariah also made an interesting point regarding this phenomenon. With respect to the exploration of the previous theoretical category and property (Chapter 7), Mariah's constructs (L76-78) referred to the wish of 'staying childlike', and is underpinned by the initial coding of 'wishing to be a child again'. In this construct, Mariah explicitly elaborated on her annoyance relating to the attitude of innocence, referring to her observations of other patients during her stay at the in-patient unit (L215), which is underpinned by the initial coding of 'others are annoying me with their eating behaviours' and 'judging other people's behaviours'. This suggested a twofold perspective. There is a mental development in adulthood in the rating of other people's behaviour, as well as the glorification of a childlike position for herself, which suggested a fluid adaptation. With this in mind, I decided to write a memo on the subject of 'innocence' and 'staying childlike', in order to explore their similarities and differences (see Memo 9 below:

Memo 9: 'Innocence' and 'staying childlike', are they similar?

The phenomenon of 'innocence' in eating disorders is often seen in the behaviours and the constructs of patients. The literal concept of innocence refers to 'without guilt', but also to naivety, silliness and unrepentance (https://www.encyclo.nl/begrip/onschuld). Regarding the phenomenon of innocence in the context of the SE-AN women, 'unrepentance' seems to cover the meaning n the elaboration of the property according to 'innocence', and is pursued by the SE-AN women. In the assessment of one's own behaviour, innocence creates a seemly safe place in the women's minds, it mitigates the process of adaptation regarding SE-AN and, as a result of this, the status of 'innocence' is nurtured, and if necessary, defended by the women, whereby it is difficult to objectify such behaviours together (patient and professional).

In constructs, the patients exhibit innocent behaviour, which often led into 'getting what you want', or, even more often, into 'getting what the eating disorder wants'. Moreover, this concept is substantial in the development of manipulative behaviour through innocence.

The constructs referring to the childlike behaviour are partly composed by the views of others, as well as their own view. With this, innocence is an accompanying factor in the adaptation of SE-AN, and it is considered an interpersonal concept.

Concerning this theoretical finding, I consider 'innocence' as a substantial underpinning in the exploration of two theoretical categories: 'one step forward, one step backwards', and 'I will always be the girl with the eating disorder'.

Memo 9: Exploration of staying childlike and innocence

The memo above provided an insight into my personal thinking process when considering both the phenomena of 'staying childlike' and of 'innocence'. Although the concepts are not exactly similar in the context as seen in the SE-AN participants, I nevertheless concluded that both concepts in this context are related to each other, in that 'staying childlike' is constructed by the patients and their social environment, and that 'innocence' is the self-experience of the women. Thus, elaboration of the property contributed to the previously developed property of 'I will always be the girl with the eating disorder', and thus, the initial codings contributed to the two theoretical categories: 'suffering, but not in silence' and 'one step forward, one step backwards', whereby an inter-related relationship is revealed between the categories.

In conclusion, the exploration of ‘innocence’ contributed to the development of the theoretical category, ‘one step forward, one step backwards’, hence, ‘innocence’ contributed to the ‘childlike’ approach, and thus it strengthened the influencing factors with regards to the diminished quality of life experienced by the women participants. In the next section, I elaborate on the exploration and dimensions of the second property, ‘guilt & shame versus recovery & success’.

8.4.2 The second property: ‘guilt and shame versus and success’

8.4.2.1 Guilt & Shame

The analysis of the previous property directed my insight into the next closely-related second property ‘guilt & shame’ versus ‘recovery & success’. In this section, I start with the exploration of the phenomena of ‘guilt & shame’, since both warranted attention in the women’s interviews. Although the concepts of ‘guilt and shame’ are often used in the subculture of eating disorder patients, more often, the two concepts are used interchangeably at the SEDU. To clarify this aspect, a memo (Memo 10) was written:

Memo 10: Exploration of Guilt and Shame
The feeling of ‘guilt’ focuses on ‘*what people do’,* while *‘*shame’ focuses on *what people are.* The relationship between the phenomena suggests the harmful behaviour towards other persons, (referring to guilt) and turns into shameful behaviour against others (referring to shame). Thus, regarding to the ‘guilt phenomenon’, it should be easier to cope with, as seen from a more objective perspective; after all, the experience of ‘guilt’ is related to certain behaviour against another person. According to the feelings of ‘shame’, it is considered as a more subjective emotion in which distance, and reversely, proximity plays a major role. Hence, engulfment, (close proximity) strengthens the ‘shame’ emotion, and conversely, if the social distance between people is too large, the ‘shame’ emotion finally isolates people, regarding the fact that the person with the ‘shame’ emotion cannot ‘bridge the gap’ due to the experience of it. Then, people who do not want to be in the ‘social spotlight’. They often develop certain feelings of ‘guilt and shame’, and it is the ‘shame’ experience which is often accompanied with certain feelings of failure and uncertainty. Finally, the ‘shame’ experiences do affect the reality where people live in (Schalkwijk, 2012). Hence, ‘guilt and shame’ are frequently discussed themes during therapeutic sessions. I personally think that ‘guilt and shame’ are important factors referring to a relapse or stagnation in therapeutic processes. The persistent beliefs related to’ guilt and shame’, seem to work infectious, as well in other domains of life and in the contact with other persons. Thus, ‘guilt and shame’ are entwined in the social world, in contacts with others, and in daily activities. Moreover, are highly responsible for whether or not being successful. In conclusion, ‘guilt and shame’ within SE-AN people are *bread and butter* which made the theoretical finding of ‘guilt and shame’ a significant underpinning in the construction of the

theoretical category in this study. Despite the differences in both concepts, regarding to 'guilt and shame', the SE-AN people often experience a blurred mixture of the feelings.

Memo 10: Exploration of guilt and shame

Memo 10 proposed an insight into the significance of the theoretical finding. Thus, I decided to include the finding of 'guilt & shame' in this project. Furthermore, the memo underpinned the decision to consider the concepts of 'guilt and shame' as an important finding in the exploration of phenomena, as seen through the constructs of the SE-AN sufferers.

Nevertheless, in order to make the theoretical finding even more robust, and to prevent the project against bias, it was challenging to search for the validation of a strong relationship between the concepts of 'guilt & shame' as the narratives had indicated, although an appropriate elaboration of this theoretical finding from the interviews is signalled. In the realisation of this recommendation, I returned to the original verbatim interviews, which combined the conceptual mind map of the initial codings with the search for code words, such as 'guilt', 'shame', but also 'disgust', and this provided a guide to the elaboration of the initial codings. Furthermore, the original messy mind map (Appendix 7.2[46]) was used in connection with the maintenance of the overview of the data gathering. The data elaborated on the women participants' statements which refer to the adaptation of their feelings and, in turn, to their experiences of 'guilt & shame', in relation to their societal position and their SE-AN condition. To illustrate this belief, excerpts from Sophie, Sandy and Mabel were added:

> *"I feel myself very bad and guilty, when I haven't done enough exercise and also fear, fear of gaining weight, the fear of getting fat, the fear of being rejected and even a piece of disgust over myself, I can feel that. Like I am really dirty, like I literally cannot be with myself. Thus, in order not to feel that scale of things, I surrender to the ED. And is like a system, a mechanism."*
>
> (Sophie: L43)

---

[46] Appendix 7.2: Messy mind map of the theoretical findings, 'One step forward, one step backwards'.

And, in the relationship with her boyfriend:

> *"His friends don't know about my situation, for me it's different when I meet them. On one hand it's annoying, that I have to lie and that I should be ashamed of some kind of a situation, meanwhile, I don't want to be ashamed of the situation anymore."*
>
> (Sophie: L70)

Later, Sophie made a strong statement concerning her SE-AN condition:

> *"I feel ashamed about myself, about my condition".*
>
> (Sophie: L82)

The excerpt below from Mabel referred to her feelings of guilt when she allows herself to take some rest:

> *"I feel very guilty. I feel guilty by lying on the couch or in bed. Like, someone else is doing something that I need to do. If I take that load, I make it possible for the other that he or she can take some rest."*
>
> (Mabel: L86)

Then later, Mabel linked her guilt with 'feeling fat', which was evoked during the eating moments, and thus, an 'in vivo code' was revealed:

> *"I feel so fat and guilty with every bite."*
>
> (Mabel: L160)

In Sandy's case, she connected her guilty feelings to her dog:

> *"Then I take a look at him, (the dog) it is a dog who needs to walk and must be challenged, I feel so very, very guilty".*
>
> (Sandy: L56)

And Sarah referred to her hidden behaviours which had damaged her relationship with her parents:

> *"I went back moving in with my parents because I had to, my parents can live with me but not with my eating disorder, too many conflicts popped up, it's about eating, cooking, eating all the food on the plate, things like that. It's hard to force an adolescent but that situation, regarding the 25 year old woman that I am now. It was despair, my dad told me, you eat what's on your plate, or you get your stuff and leave. At the*

> *moment they told me that, the switch was off, I could only think, "I will get my stuff and leave", "figure it out". About my behaviour, I noticed the sadness of my parents, they felt broken. I've made the decision, I will work it out by myself, so I can protect them against the pain of having a daughter who is ill".*
>
> (Sarah: L49)

The exploration of the excerpts elucidated the feelings and the experiences referring to 'guilt & shame'. In the excerpt from Sophie, she clearly stated the experience of guilt if she did not meet the requirements that the eating disorder imposed on her. The initial findings, such as, 'defining the eating disorder influences the whole day', 'defining punishment 'through' eating behaviours', 'connecting eating rules with exercise' and 'guilty feelings', empirically underpinned the property. Conversely, Sophie just did not want to take account of her status as an anorexia patient in every situation. She had found a solution to this, in that she no longer explained her AN condition to others. The initial coding 'stop defending my position' refers to this specific excerpt. Within Sophie's last statement, she clearly stated the burden of being a SE-AN patient. With this, Sophie stated her feelings referring to the prevailing opinion in the society according to SE-AN patients. The initial codings, such as 'defending my position as a patient', 'defining how women should present themselves to the world' and 'others judging me because of my illness', function as the empirical underpinnings. Regarding Mabel's statement, she related her guilt to the belief that she would 'carry the load' for others, which is a more abstractive expression. However, Mabel gave expression to this statement by her constant cleaning and her refusal to take some rest. Thus, the initial codings, such as 'cleaning' and 'not deserving any rest', suggested a metaphor in terms of 'see me', 'need me' or, on a more abstractive level, 'I am'. The closely related supportive initial codings made this assumption more robust and, therefore, more transparent with regards to 'experiencing failure when I cannot meet self-imposed activities', 'not deserving any help' and 'defining the load of others according to my situation'. This rationale suggested the 'adaptation of the AN condition', and conversely, to losing the status of the AN condition to 'not being seen'. To give an appropriate explanation for the rationale, the model below (Figure 8.4) illustrates a cyclic process, which is built on the initial codings and which, in turn, leads to the adaptation of the AN condition as a reason 'to be'.

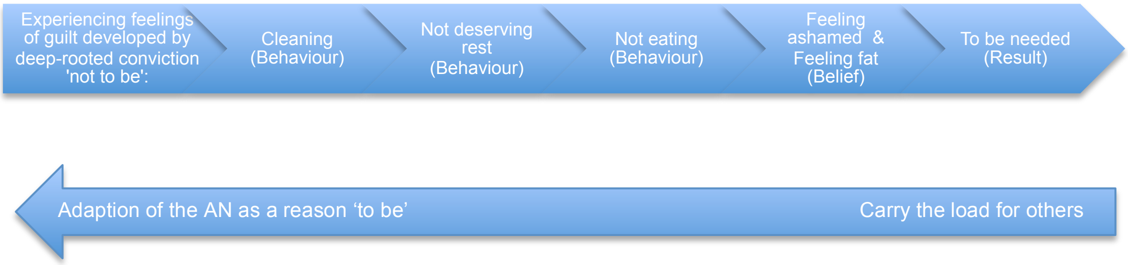


Figure 8.4: Cycle of adaptation to the AN condition

A further interesting phenomenon is the deep-seated belief relating to 'guilt', whereby in terms of eating, every bite of food exposed the guilt experience and the abstract concept of 'feeling fat', which is also an 'in vivo' code in the text, because of the language the women participants use in their social world and, thus, the code works as a symbolic marker (Charmaz, 2006). In Mabel's case, she suggested that there had been insensitivity in terms of the general ED therapies she had been exposed to in the past. Regarding the extant literature, which is not a problem integrate them at this point of the study as long as the initial codings are grounded in the data (Charmaz, 2006), the experience of guilt seems to be ingrained in their thinking strategies, which is often recognised in people with SE-AN (Tchanturia, 2014; Touyz et al., 2013). This concept is also seen in Sandy's excerpt (L 56), where she experienced a convincingly guilt according to her dog.

Sarah also elaborates on her feelings of shame and guilt in the relationship with her parents, whereby her feelings are concealed in an anecdote relating to her eating behaviours and the impact this has on the family. This is in line with current theories relating to guilt and shame (Schalkwijk, 2012), and it suggests some objectivity, since a connection is detected between certain 'shameful' behaviour towards others.

Again, regarding the extant literature, according to Charmaz (2006), it is not a problem to sporadically add literature findings during this stage of the study process, that is, in the findings chapters, as long as the findings are sufficiently grounded and that the insertion of extant literature findings during the data analysis is considered as additional data (Charmaz, 2006). Thus, to assure the current study's findings in relation to shame, Kelly & Tasca's (2016) research was examined, in which they argued for the existence of a strong cyclically influential relationship between shame and the eating disorder pathology. Likewise, Goss & Allan (2009) concurred with the view of this relationship, however, according to their research, shame is a complex, dynamic, variable and self-conscious emotion. Shame and its opposite, pride, are often both seen in diverse coping behaviours (Goss & Allan, 2009). Emotions, such as pride, can be experienced as a result of resisting impulses related to eating. Shame, on the other hand, is experienced if one's own eating rules are exceeded, whereas pride can be linked to eating disorder behaviours (Goss & Allan, 2009). These findings are in accordance with the study findings of Troop & Redshaw (2012), although in this study there was a single focus on bodily shame in terms of the outcomes. Bodily shame appeared as a predictor of the increase in the degree of being underweight and, in addition, it predicts the increase in the fear of weight gain in people with Anorexia Nervosa (Troop & Redshaw, 2012). A constructivist study by Nunn (2009) indicated the relationship between shame and being judged by others, based on the assumptions of other people's thoughts while observing a patient with an eating disorder. The following findings corresponded to a situation which Mariah described in her interview:

> *"I see that people are talking about me.*
> *I: I think it's very painful, what do you think in those situations?*
> *M: That I haven't got the right to exist. I know very well, last year I visited a festival, it was a victory for me, I won tickets for the 'Concert at Sea' Festival, I decided to visit the event, which felt like a victory because of the crowd. However, I had never visited the festival before. So, my friend said to me, the tickets are for free, we are going to visit the event for a short time and when you've had enough we'll leave immediately. We did it like that, and then, we were in front of the stage of Anouck (Dutch singer). And then I started to dance, and uuuuhm, I looked behind, and found out that people were laughing and making a film of me with their phones. Filming and laughing and it hurt me so*

> *much. I thought it was terrible. It was so painful. And my friend said, come on, let it go. But I said, 'I've had enough, I really want to go now'. Just leave."*
>
> (Mariah: L60-62)

Later, Mariah's construct explained her guilt when she referred to her thoughts about not having to live like this:

> *"When I die of Anorexia, then it will be like that, that's something I can't influence and then I don't have to feel guilty about it."*
>
> (Mariah: L271)

The first of Mariah's excerpts described a painful moment she experienced, where people were making fun of her and were laughing at her. The situation revealed the feelings of shame and guilt, as a result of her thin appearance and, therefore, the attention she received over her dance moves. Mariah was convinced of her guilt, and it was she who drew attention to this, and which caused her abrupt decision to leave the festival. She used this action as a coping mechanism to deal with the situation. In addition, she also experienced an increase of guilt towards her friend. Thus, the situation itself has led to an increase in Mariah avoiding social situations. Then, in the second of Mariah's excerpts, relief is implied. In this instance, there is the suggestion of redemption from the experiences of guilt and, because of the AN condition, she would not be to blame for her death. In this potential scenario, it was as though she could do nothing to prevent it. Although this is a delusion, a certain objectivity is identified, in that death is a specific solution that would put an end to the situation. With regards to the number of 'death' theme references, I decided to write a memo (Memo 11) on the topic, which is shown below.

Memo 11: Death
Regarding the interviews, the theme of death was proposed a few times, despite the fact that I have not chosen to expand upon this topic. Nevertheless, on account of the impact of the subject, I decided to focus on the death theme in this memo because of the continually present of the topic present in the contacts I have had with the SE-AN women. Then, a verse in the poem Amy wrote illustrates the underlying appearance of it, and is as follows (L:159-161): *"I feel the strings are tied up. Tied up because the puppet cannot stand any longer by itself. My willingness*

to give up comes near and it seems that dead is the only redemption".

Thus, during treatment, the subject of 'death' is often discussed once patients feel 'safe enough' after I assured them that I will not approach the theme by taking immediate interventions as seen from the perspective of 'control', such as increasing the supervision of the patient by the professionals. The search for this assurance is related to traumatic events, which are caused by forced tube feeding, fixed to the bed. Especially the women aged 40 and over are familiar with psychiatric coercive measures, deployed to prevent them from dying from the consequences of the eating disorder condition. Despite the fact that they are still living, most women remembered such treatment as highly traumatic, especially the forced feeding, mostly by gastric tube, given as a regime of punishment and rewards.

Yet, despite this former approach, there is still no consensus of how general mental healthcare professionals should treat people with SE-AN. In practice, I noticed there are still professionals who are convinced of a more orthodox treatment approach; re-nutrition by coercive measures, and although well-meant and life-saving, the people with SE-AN did not feel heard or sufficiently understood in their suffering. And regarding the current findings of this project, the SE-AN women know that they are suffering from a psychiatric disorder, which does not mean that they are not capable of making a realistic estimation of their personal situation (Elzakkers & van der Linden, in Noordenbos & Elburg, 2018).

In conclusion, it is possible that the former treatment approach, using coercive measures has contributed to keeping appropriate treatment at a distance and thus this contributed to a diminished quality of life. As a result, I consider the theme of 'death' as significantly noteworthy in the treatment of the SE-AN population.

Memo 11: Theme death

Regarding the memo (Memo 11) above, I consider the elaboration of the death theme as important with regards to its influences on current healthcare professionals, guidelines and possible policymakers. The memo illuminates the effects of forced treatment and the potential permanent damage caused when considering the thinking processes of the women SE-AN sufferers, in that it is of significance in their request for professional care. In conclusion, it contributes to the request for a better approach by the professionals to the women SE-AN sufferers.

Next, the analysis progressed by seeking discrepancies in the property, which led to the exploration of the women's constructs in their social situations. In the following excerpts, Violet talked about her constructs as to how others experienced her AN condition:

> *"I: Do you receive comments from others?*
> *V: Only from my father when he feels powerless.*
> *I: What does he say?*
> *V: That I am ugly in my thinness.*
> *I: What do you think of that?*

> *V: I think it's annoying. And then I interpret it backwards, I can think, I know that I am worthless and ugly and the next thing is losing myself in negativity. And then I don't dare to speak to him which makes our contact worse. Finally, we talked it through but it takes some time to get there."*
>
> (Violet: L159-164)

Shortly afterwards in the interview, Violet elaborated on a situation with her mother:

> *"She takes the time for it, however, she is doing a study now and in some kind of a psychotherapeutic way she asks me questions but that irritates me in terms of 'Mom is playing the role of being a psychotherapist' and I don't want her to do that. So, I want to stop these kind of conversations and I say; Mom, don't act like that, I don't want you to."*
>
> (Violet: L170)

Violet also explained how she experienced contacts with others:

> *"I: Do you feel taken seriously? And if not, would you say it?*
> *V: That's exactly the point, I don't say it. So, others can't take me seriously because they don't know me well enough, I don't tell them."*
>
> (Violet: L183-184)

And later Violet talked about how other people appealed on her emotions in contacts:

> *V: People who react directly or make intense reactions to me touch me. Then I feel hurt and sad and bad, because I think it's my fault. I stand in their way. Some conclusion, what others think of me, influences me very much, and then I hide. I don't want to meet them, I try to avoid them, and that is why I think it's difficult not to cry when they make comments. Because when it touches me personally, I feel emotional."*
>
> (Violet: L198)

And her reaction, when referring to her AN condition through the lens of others:

> *"I: And if you think about your position of being an Anorexia patient, how will people react to that? Do they think that it has to stop?*
> *V: Yes. Especially my dad and grandparents.*
> *I: Your next of kin?*
> *V: My dad says, let it go.*
> *I: And how does it work for you?*
> *V: Then I think, if it was that easy!!!"*
>
> (Violet 209-214)

And Mariah talked about her constructs according to how other people approach her:

> *"I followed the treatment programme, did it for others only, and it didn't work for me, because I did it for them."*
>
> (Mariah: L72)

Then Mariah referred to a distance that her parents took from her:

> *"My parents wouldn't want me living at home."*
>
> (Mariah: L80)

And she explained how she felt when she was approached at work:

> *"I: Your eating disorder helped you to get through that dark period?*
> *M: Yes definitely, after that point, they never treated me as an adult (colleagues). I had lots of stress and an urge to prove myself to others at work."*
>
> (Mariah: L93-94)

Then Mariah explained her role in creating a distance from others:

> *"And I don't experience things anymore, I'm only busy with eating and non-eating. Walking, non-walking, I don't have any useful things in life, I can't do nice things, can't share nice things, I am only the ED. I try to listen to others and react to them but it won't work, I don't have anything."*
>
> (Mariah: L229)

And how the opinion of others in terms of her SE-AN condition affected her:

> *"I personally think that lots of people don't want to see this kind of suffering. They don't take their responsibility to understand it and, it really hard to explain my situation to others. I don't even understand it myself."*
>
> (Mabel: L72)

Then, Mabel explained her belief of being a burden to others:

> *"I'm good enough for decoration. And I don't like getting presents, I feel so unsure. I think to myself, let's get it over with. It's not necessary. I always asked myself, why do people give me presents? I am a burden. I don't deserve that, never. And also, if have eaten enough and people said to me, well done, that feels so wrong."*
>
> (Mabel: L93)

And she explains how she responded internally to compliments:

> *"I: Compliments from others, what do they mean to you?*
> *M: I don't believe them."*

(Mabel: L94-95)

Mabel showed an insight in to how she deals with compliments:

> *"I've always had trouble with receiving compliments. I've never felt any self-confidence. I have trouble with trusting people. That's really hard."*

(Mabel: L101)

The initial codings, such as 'difficulties with receiving compliments', 'not believing compliments', 'I am a burden', 'others are not taking the responsibility to understand the situation', 'keeping others at distance', 'others keeping distance from her', 'letting the eating disorder go', 'not taken seriously' and finally, 'others are defining me as ugly' all contributed to the focused codings of 'guilt & shame' and made the data grounded. A subsequent e-mail exchange with Violet allowed me to gain a greater insight which, in turn, led to further memo writing whilst focusing on a situation where guilt and shame were reciprocated, and is illustrative of the property of 'guilt & shame' (see Memo 12).

Memo 12: Violet versus guilt & shame
Violet and I agreed that she should mail me if she wants to get something off her chest. In her mail, Violet explicitly explained the pressure she felt from others as a result of her eating behaviours in the in-patient setting. Violet told me that during meals she felt spied on and, because of this, it was no longer possible to stick to her meal plan. At first, we talked through the possibility of temporarily eating meals in her room. However, Violet told me that would be more shameful, because others might think that she was doing this on purpose and, with this, there would be the possibility of her not sticking to her meal plan. So, this solution would increase the guilt against others (I betrayed them) and the shame, because of the act of choosing to eat alone. Whichever way, it did not matter, guilt and shame are held in a delicate balance and both confirmed ingrained thinking strategies.

Memo 12: Exploring Violet's excerpt

Memo 12 illustrated an insight into the thinking process and how I made the decisions in the study process, supporting the validity and transparency of the thesis. Furthermore, the memo supported me in the following conclusion, that there is a cyclic tension within both phenomena, guilt and shame, and, as a result, I decided to regard the two phenomena as one.

Exploring the diverse dimensions of guilt and shame illuminated several initial codings which referred to the topic. Comparative analysis allowed the matching strategies to be advanced in terms of people with SE-AN. A clear overview is shown in Table 5, which illuminated the corresponding thoughts and the daily activities involving ‘guilt and shame’. In the comparative analysis, the matching ‘core eating behaviours’ were found. It became apparent that the current core behaviours are firmly based on the beliefs related to judgment of self. The analysis indicated that daily ‘core eating behaviour’ activities became predictable. Thus, this suggested a strengthening of the SE-AN condition and underpinned the constant cyclical influences.

Table 5: Comparative analysis: initial codings of guilt & shame, thoughts & behaviours

Name	Initial codings developed by thoughts	Initial codings developed by behaviours
Mabel	• Guilty feelings • Experiencing failure when I cannot meet self-imposed activities • Not deserving any help • Feeling fat (in vivo) • Difficulties with receiving compliments • Not believing compliments • I am a burden (in vivo) • Others are not taking the responsibilities to understand the situation	• Carrying the load for others • Excessively cleaning • Deserving no rest • Not eating
Sarah	• Feeling ashamed against my parents • Experiencing guilt against parents	• Protecting parents against disappointments by avoiding them • Increasing hidden behaviours
Mariah	• Experiencing shame because of my appearance • Experiencing guilt because of the decision to leave the festival • Wishing to stop feeling guilt against my illness • Keeping others at distance • Others keeping distance at her	• Avoiding contacts with friends, parents • Less eating • Intensive exercising
Sophie	• Feeling bad and guilty • Feeling ashamed of the situation • Others are judging me because of my eating disorder • Defining that the eating disorder influences the whole day • Connecting eating rules to exercises	• Defending my position as a patient • Defending how SE-AN women should present themselves to the world • Defining punishment ‘through’ the eating behaviours • Less eating • Intensive exercise
Violet	• According to father: Let go of the eating disorder • Not taken seriously • Others defining me as ugly • Not knowing what to do (memo 11)	• Less eating • Intensive exercise • Intensive cleaning

In the previous excerpts, I explored the experiences of ‘guilt & shame’ of the women participants. According to the excerpts, guilt explained the feelings that were experienced in respect of relatives, whereas it is suggested that shame is entwined with the interpersonal feelings relating to personal behaviours and bodily appearance.

Both phenomena suggest a relationship with weight loss, or maintaining a low weight, and thus, ‘staying ill’, which conforms with the extant literature on the topic. Moreover, as in the interviews, shame and guilt are often concealed within metaphors and in coping behaviours

(Goss & Allan, 2009), and finally, shame and guilt confronts SE-AN sufferers with their fear of weight gain (Troop & Redshaw, 2012).

8.4.2.2 Recovery & Success

The following section details the insights and the components of the theoretical category of 'one step forward, one step backwards'. As in the case of 'guilt & shame', which was explored in the first part of the property, the second part of the property revealed the discovery of 'recovery & success'. With this, the dimensions of this property will be defined. Firstly, I underpinned 'recovery & success' by the empirical findings of the interviews. The early codes, for instance, 'feeling healthy again' and 'meeting expectations', identified major theoretical codes, such as 'recovery' and 'reciprocating love'. These codings, embedded in the narratives of the women participants, function as the empirical underpinnings of the theoretical category. During the interviews, although most of the women did not specifically refer to weight gain and recovery, Fiona often mentioned the importance of weight gain and what it brought to her. Fiona gave a clear explanation of her experiences with regards to weight gain, which is illustrated by the excerpts below:

> *"I have known a period when I was partly recovered, my weight was higher, better. I noticed that I was a lot happier, joyful, less emotional, less emotionally unstable. I dealt with my life then. So, I want to say that it is very important to recover the weight so you can experience more power to fight against the eating disorder."*
>
> (Fiona: L38)

Later in the interview, Fiona underpinned her statement again by stating that gaining weight is an important factor in defeating the eating disorder:

> *"And I know how my eating disorder works, how the puzzle has to be made. How it has arisen but it doesn't say that it's easy to get over it. Despite that, I am underweight, luckily only a few kilos, but with this, the eating disorder is in the lead, so, it is so important not to lose weight again, to stabilize a weight that's good for me. I've never thought that a few kilos of weight loss could strengthen the eating disorder."*
>
> (Fiona: L40)

Subsequently, Fiona underpinned her view again:

> *"With a few kilos of weight loss it dominates my life again in a way that it is not livable."*
>
> (Fiona: L42)

And she repeated herself once again:

> *"I want to gain weight because it gives me so many more possibilities."*
>
> (Fiona: L61)

In her construct, Fiona experienced a better quality of life during an episode when her weight was normalized:

> *"Then it's hard to imagine what it is to be healthy and happy. I know, when my weight was normalized, I experienced my life totally differently, I cannot picture that right now, it's fading."*
>
> (Fiona: L62)

Conversely, Fiona stated her experience with weight loss and the consequences of it:

> *"There is a constant fight going on, this is very big. Yes. It's so hard to oppose these thoughts, while you are getting weaker, losing weight, the eating disorder is taking the lead. My rationale is becoming smaller, it's pushed aside."*
>
> (Fiona: L65-66)

Then, as a conclusion Fiona stated the importance of therapeutic help to assist in defeating the eating disorder:

> *"I'm really thankful that you've given me the chance for treatment and support and I hope that, maybe, if needed, that you will be able to give me this kind of treatment again. So that makes me able to work further on my recovery. All I want is to beat the Anorexia Nervosa."*
>
> (Fiona: L119)

In these excerpts from Fiona, she strongly advocated gaining weight if AN patients wished to recover. In her case, she experienced that the maintenance of being slightly underweight did not lead to persistent improvements and subsequently, it predicted another relapse. Thus, 'defining the importance of weight gain', 'gaining weight is less depression' and 'feeling healthy again' all functioned as the initial codings, which made the data grounded. This phenomenon is in accordance with many existing sources and guidelines in the treatment of eating behaviours, and restoring weight is a significant finding in the recovery of AN (Hay et al., 2014; Zorgstandaard Eetstoornissen, 2016; NICE, 2017). Nevertheless, this is precisely the apparently unbreakable chain of persistent thoughts pertaining to weight, food and body shape that is experienced by SE-AN sufferers (Touyz et al., 2013; Noordenbos et al., 2000).

Conversely, a rather long excerpt from Sarah referred to the loss of success in life versus the strengthening feelings of ‘guilt & shame’. Sarah developed her eating disorder during her adolescence and, as a result, she was not capable of combining her studies and her therapy to try to defeat her AN. Finally, she fled into the AN to keep herself standing:

> *“I don’t know, but studying while having an eating disorder is too much load to carry. In my first year, I studied full-time, meanwhile I followed day treatment for 3 days a week, after school. I stopped that regime after 5 or 6 months, I simply couldn’t handle that anymore, it was way too much, I had to follow the therapy and to perform in my studies and to do all the requirements. Every day, I came home at 10 p.m. I had to learn for school for the next day and that for 3 days a week, and it was breaking me up. When I think about that now, I didn’t get it why there wasn’t a person to help me and support me at that time, or a therapist who said to me; this isn’t working! Hello! This simply does not fit, and won’t work at all! So, I made a decision, I stopped all my therapies, I don’t know if that was a wise decision but I was too tired of it all. I thought, I’m going to study and everything is going to be all right. But having an eating disorder while studying, it’s too much of a load to carry. I didn’t have room in my head for studying, always busy with, okay, I’ve eaten this, and later I have to eat that, so I will be able to eat so many calories. I was only counting the calories the whole day, though, only busy with all other things connected to the eating disorder and exercise. I counted all my exercises when I sat in school. And half of what they told me during college it didn’t get through to me at all because I was thinking of a sandwich, and what I would put on it. So, it was really awful. I tried to perform three things at the same time. First, I’d try to study, second, I was a huge perfectionist, I had to get A grades, so that was an enormous pressure, and third, I was always pleasing the eating disorder. So my study time, when I did study, I never enjoyed it. I never went to parties, I had few contacts with others, that simply did not fit at all, if I had to give that part some attention, my head would explode! I went to school, I was at home, learning, and I had a small job at the weekend.”*
>
> (Sarah: L57)

The excerpt from Sarah explained her feelings of loss while gaining successes in life, such as those relating to her study, her career, and building on her contacts and friendships in her social world. However, Sarah lost her perspective regarding her professional sports career and her second choice of career to study to be a speech therapist. Sarah's excerpt demonstrated the empirical findings in the initial codings, such as, ' hiding behaviours', 'losing control', 'losing my dreams of what I wanted to be', and conversely, 'the eating disorder is giving me power'. The findings encouraged her feelings of 'shame & guilt', but subverted her feelings of 'success', which empowered the cyclical influences in terms of the maintenance of her SE-AN condition.

Next, Sandy's construct represented 'reciprocating love' as an underpinning for 'success'. Sandy is obliged to take good care of herself, and in doing so, she reciprocated love and care from other people. The first excerpt referred to her taking care of her dog:

> *"I: I think it's super that you're looking for some help? Genuinely?*
> *S: Yes, because I take it very seriously, it's a great dog and he gives me enormous support, because I have to get out of my bed and I have to take him for a walk every few hours. I take the bus to the woods, and we walk, "*
>
> (Sandy: L67-68)

After a while, the dog became the topic of conversation again:

> *"Eating isn't easy, but after all, it's getting better because of the dog, less binge eating, less vomiting, so, that's fine. Still, it is very difficult and when the day ends up badly, it takes two days to take back the meal plan. Tssss."*
>
> (Sandy: L133)

Later, Sandy connected the situation with the dog with experiencing fewer binge-eating moments:

> *"The dog pulls me out of the house. That's a big difference. It's firstly, let's go outside and later, let's eat. Instead of, like a fool walking to the kitchen and survive through the eating disorder."*
>
> (Sandy: L193)

Then, Sandy referred to the contact with her mother who is willing to take care of her:

> *"I've spent some time with my mom for a while now. She started to take care of me, to feed me and so on. I would not have this kind of behaviour from a stranger."*
>
> (Sandy: L251)

Excerpts referred to the process of 'reciprocating love' and 'attention in Sandy's social world'. Once Sandy demonstrated more healthy behaviour, she was rewarded by attention from her dog and her mother. Conversely, Sandy experienced lasting expectations that she could not meet, imposed by personal social structures. The excerpt below illustrated this construct. Sandy used the metaphor of 'a train where everybody takes a seat and the train keeps moving:

> *"I use to have great plans, I studied, and worked, I was in the train where everybody took a seat. That's what I wanted then. So I have done those things and finally, I couldn't hold on to it, I had graduated, had married, had a house, a mortgage, a social life, did sports, went to parties, I've done everything. But, like always, it was too much. I didn't show myself what I wanted or needed. I was doing the things everybody did."*
>
> (Sandy: L122-125)

The excerpt above met the initial codings, such as 'meeting expectations', 'experiencing the load of daily activities' and 'flee in Anorexia'. In Sandy's construct, the pursuit of success achieved the experiences of loss. With this, the initial codings indicated the underpinning of the supportive theoretical code with regards to 'reciprocating love' and, in the context of women with SE-AN in general, the codes are highly supportive of the theoretical category 'recovery & success'.

Nevertheless, returning to the findings which refer to 'reciprocating love from the dog', it was worthwhile to explore the topic further. I decided, therefore, to write a memo on this subject (Memo 13), which is given below.

Memo 13: Reciprocating love from the dog
During conversations on the ward, dogs are often a topic. Not only am I the owner of two dogs, which patients are often interested in, but many of the women I treat, share their love of animals with me. We often show each other our pet photos and, by doing this, I can search for shared values in an attempt to break the ice or to connect with the patient. In doing this, I give insight into who I am as a person. Although not everyone is interested in pets, most patients accept the conversation topic because of the accessibility of it.

Also, for the last few years, dogs have been welcomed and allowed into hospitals and public buildings. A positive lobby for 'assist dogs' in general psychiatric care has been responsible for improved acceptance of aid dogs. And although there is still some resistance, since 14th July 2016, a Dutch Act stated that aid or assistance dogs can no longer be refused access to public buildings, such as hospitals, mental healthcare institutions, restaurants and even taxis. Moreover, refusing an assistance or aid dog is punishable under the penal code (https://dogzine.nl/nl/nieuwsartikelen/hulphond-weigeren-voortaan-strafbaar). Specific policy has led to special training for aid dogs whose speciality is helping people with eating disorders and thus, from time to time, aid dogs can accompany their 'bosses' on to the ward during (in-patient) treatment. For me as a professional, I am so used to the presence of dogs in the ward that I do not even notice their presence anymore, except for the fact that I give them a hug, after I have asked permission from the owner to do this.

Regarding my findings related to 'reciprocating love from the dog' in Sandy's narrative, I discovered that, typically, women SE-AN sufferers are highly attached to their dogs, even to their pet dogs, which are not allowed on to the ward. An example of this significant attachment is found with Sarah, who was interviewed in a daily talk show, where she related her story (https://pauw.bnnvara.nl/media/396223). During the interview, her dog laid by her side. Later, Sarah told me that her dog kept her calm and safe, and that because of the presence of her dog, she was able to talk about her illness process on national television.

Another example that I did not even notice during the interviews was Fiona and her aid dog, Luka. Perhaps I did not notice Luka because of the dog's constant presence. Luka is beautiful golden retriever who never leaves Fiona's side. Her dog de-stresses her, and even appears to notice any potential anxiety that may be about to happen or mood changes by her 'boss', even before Fiona herself notices. Luka watches Fiona day and night and supports her in staying in contact with other people, simply because she needs to be taken for a walk. As a result, both Fiona and Luka eat their meals more regularly (first Fiona and then the dog), and the dog is always available. In general, the dog gives Fiona daily structure, she normalises exercise and gives Fiona unconditional loyalty, love and support.

Hence, a special educationalist is connected to the SEDU. This professional uses an aid dog, which is trained to support and to connect to people experiencing constantly high levels of stress. The dogs explicitly work on the improvement of self-confidence within vulnerable people, and furthermore, these dogs 'mirror' divergent behaviour but without any rejection from their 'bosses'.

Memo 13: Reciprocating love from the dog

Regarding the memo above, it helped to enlighten my thinking process and, moreover, the decision making related to the topics responsible for the concept of the 'quality of life'. In conclusion, the findings, which refer to the contact with dogs, and thus, reciprocating unconditional love from the dogs, are significant. A result of this, I consider the aid dog as a highly useful resource in the battle against a diminishing quality of life for people with SE-AN, as seen in the domains of social contacts, healthcare and independence.

8.4.2.3 Recovery and the quality of life

Regarding the disclosure of data of recovery and success in relation to the QoL, I wanted to explore the women's' constructs concerning the questions that were related to the possible prompts as noted in the questions, which were the following:

- *'If you recovered, how different would your life then be?'*
- *'Can you remember a time, whilst having AN, when you were happier than you are now?'* (See also: Figure 4.5: Example of Sensitizing Concepts, as used in this study).

Although I did not asked for these questions directly, the topics appeared during the conversations I had with the women. The following excerpts illustrated their women's views, I started with Violet, who said:

> *"I: And before you became ill, do you remember your life as better?*
> *V: no.*
> *I: I can imagine that concerning the bullying. And was there a time when living with the ED was okay?*
> *V: no, definitely not."*
>
> (Violet: L229-232)

In the excerpt of Mariah the topic appeared a little more concealed. After a difficult episode on another ward of an in-patient setting where the treatment did not focus on the eating disorder, she said:

> *"I: So, they decided that you can't come back for care?*
> *M: Yes, I received a time-out, I formulated binging, gained weight, and then I started in the day treatment setting then. There it was a little bit better. Other patients where much more normal, they didn't have the extreme eating issues struggling with. Also, the people were nicer for me, because they weren't picking on me."*
>
> (Mariah: L75-76)

However, according to Mariah's story, she did not remember an episode where she had fewer psychological problems:

> *"I: Do you remember a time that the ED wasn't on the front?*
> *M: I can't remember the time.*

> *I: So, you experienced the ED for such a long time then?*
> *M: Yes, and before that, I went ill, I suffered from a social phobia, I never had any friends, I was always alone, always hiding in my room, seriously, I was always alone."*
>
> (Mariah: L151-154)

And Sophie referred to an episode when she had fewer psychological complaints to struggle with, when the ED was more in the background:

> *S: "I noticed, when thinking of the first few treatments, it was much easier to let it go, those eating habits. I noticed, the longer you are ill, the harder it will be, the tougher became the eating rules. Once, after my first treatment, I had to do exercise on daily basis but there was a maximum of half an hour per day. It was not so much comparing to my current daily exercise. I would give anything now if I could do that again. And of course, I was not recovered then, but it has been never that anymore.*
> *I: That's really saying something."*
>
> (Sophie: L47-48)

And Amy stated when asked about improving her quality of life:

> *"I: And what is a better quality of life? What does it mean to you?*
> *A: At the moment, it's not that I have to recover totally, but, normally, uuuuhm, normally, it would be nice if I do not have to deal with the eating disorder in my head all day long."*
>
> (Amy: L99-100)

She also appeared to have a solution:

> *"I: So you say, as some kind of a conclusion; not only the specialised care givers should listen better, and look after the individuals, but even the general caregivers should look better behind the severity of the problems?*
> *A: Yes, I think that all kinds of caregivers should receive education about eating disorders. It is a stigma".*
>
> (Amy: L255-256)

When Sarah was asked she referred to a period of better functioning, stating:

> *"I: And do you remember a time when you when functioning better, or is that now?*
> *S: Yes, that's now. I've made a switch a few weeks ago. Before that, I've had a very awful episode, I relapsed and thought, it is precisely before my inpatient episode, what has happened. I had a discussion with my therapist, I thought: this is what I don't want to experience*

anymore. And the current situation benefits my relationship. It gave too much pressure on the both of us that we were thinking of breaking up. And, looking at myself, I really don't want to have another in-patient treatment anymore. I must have a clear plan for the future and it will not be there if the situation repeated."

(Sarah: L72-73)

This was in clear contrast with the answer given by Mabel, during the conversation about her physical complaints:

"I: If you haven't had all these physical complaints, would your life be better then?
M: I don't think so, it's in my head, and it's gone."

(Mabel: L110-111)

Finally, Sandy said, referring to better times:

"I: Do you remember a time, while you're ill but you were happier than now? And what was different in those days? Do you still remember that?
S: I felt better, more energized, but not happier. I had, despite my eating condition, a normal weight, and therefore, I've had the energy to practice sports. Nowadays, I don't have the energy anymore; I cannot practice sports and yoga."

(Sandy: L232-233)

With regards to my questions about 'recovery' and 'improving the QoL', the excerpts revealed some substantially different insights. Violet (L229-232) did not refer to the experience of 'better times', which Mabel did (L110-111) and Sandy (L232-233), whilst Sandy claimed a clear improvement of her physical condition, a point appeared when she fled back into her anorexia, despite the fact that her QoL had became worse, and she could not practice her yoga anymore. Amy and Sophie both stated that the improvement of the QoL is less burdensome in terms of acceptance, such as 'the acceptance of some influences of the ED'. Amy (L 255-256) proposed a solution; she clearly stated that healthcare professionals should have more knowledge referring to the SE-AN condition. With this, Amy is convinced that possibly help would be better organized with regards to a better understanding which might contribute to the benefit of the treatment of people suffering from the SE-AN condition. Moreover, during the study, Sarah (L72-73) benefitted from the in-patient setting, her story supported the benefit of this treatment; she claimed partial recovery and implied that a well-considered offer of treatment with shared decision-making sometimes appeared as a suitable option. In general, the data explored the dimension of recovery with regards to the QoL. With this, the following initial codes were revealed which made the data grounded and thus empirical, and were; ‘accepting the AN’,’ fleeing in the anoxia’, ‘experiencing weight gain and the positive effects of it’, ‘learning to deal with the ED condition’, and finally, ‘asking for specialist education to caregivers’. The initial codes highly supported the theoretical finding of ‘recovery & success’ and thus the opposite, ‘the maintenance of the SE-AN condition’.

To clarify these general insights with regards to ‘guilt & shame versus recovery & success’, I have demonstrated them in the illustration below, Figure 8.5. The figure represents a ‘weight continuum’. The arrow to the left suggests the cyclically influential relationship between the factors of guilt & shame and the fear of weight gain. The right side of the figure represents the related forces in respect of weight gain. In this model, all the findings are responsible for the maintenance of the SE-AN condition.

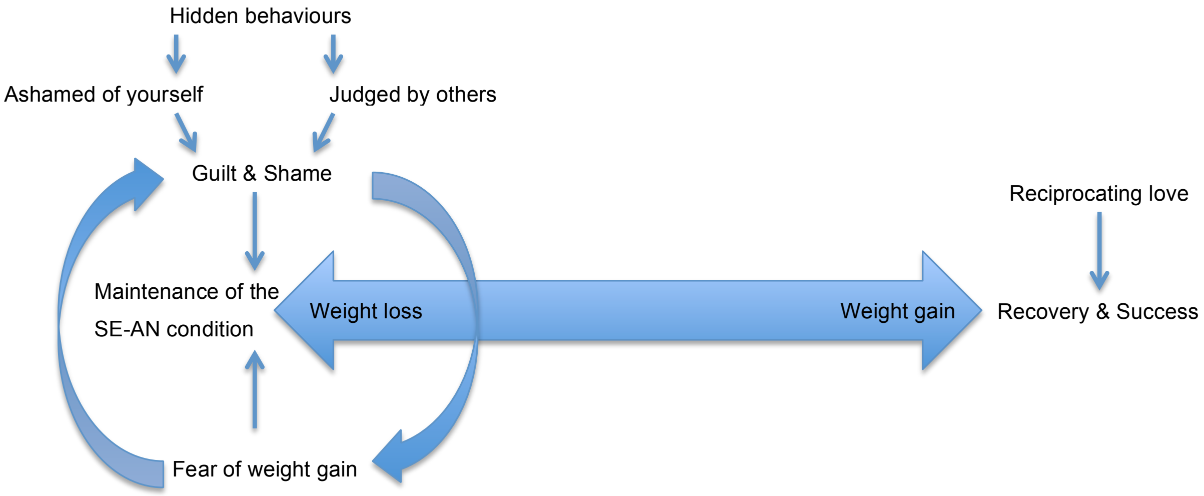


Figure 8.5: The model of the weight continuum

Regarding the current section, I revealed the dimension and the properties of ‘guilt & shame’ versus ‘recovery & success’ within the women SE-AN sufferers. I carefully underpinned the theoretical codings by the initial findings to make the data grounded. Furthermore, the findings are consigned to and compared with the extant literature. In this way, I secured the property of ‘guilt & shame’. This allowed, the opposite of this property, ‘recovery & success’, to be revealed.

In conclusion, a more in-depth search, to give meaning to the main category of ‘one step forward, one step backwards’, is achieved by the exploration of the dimension referring to the property of ‘guilt & shame versus recovery & success’. In the dimension of ‘guilt & shame’, the notion of ‘rejection’ was also revealed, through the concept of ‘judgement of self’. In addition, by exploring the dimensions of ‘recovery & success’, ‘reciprocity’ and ‘adaptation’ of the SE-AN condition emerged. The interaction between the findings suggests a responsibility in the cyclic process in the chronic condition, which influenced the quality of life that the women SE-AN sufferers experienced.

8.5 Summary

In Chapter 8, I presented the construction of the two properties, supported by the initial outcomes of the analysis to make the category of ‘one step forward, one step backwards’ grounded. The analysis through the exploration of the properties made the data significant, as well as identifying a personal and complex structure in the women participants. The analytical interplay by the constant comparative analysis revealed several core eating disorder beliefs, which suggests a constant pressure on the adaptation versus rejection of the AN condition. In this way, the key findings of *‘Innocence’* and *‘Guilt & shame versus recovery & success’* appeared through the lens of the weight gain-weight loss continuum. Next, the analysis revealed a cyclical process, where a delicate balance exists between ‘guilt and shame’ and, subsequently, ‘the fear of weight gain’. This balance appeared to be responsible for maintaining the feeling of guilt and shame. Typically, the data indicated that this process is counterproductive in the recovery of the patient, and thus, it is suggested that this process is not successful. Subsequently, in this chapter, I revealed the property of innocence, thus, SE-AN people adjusted an innocent approach through adapting the SE-AN condition. Next, the exploration of ‘innocence’ contributed to the development of the theoretical category ‘one step forward, one step backwards’. Moreover, ‘innocence’ contributed to the ‘childlike’ approach, and thus, it strengthened the influencing factors with regards to the diminishing quality of life experienced by the women SE-AN sufferers.

In the second property, multiple themes were explored, such as ‘guilt & shame’ and ‘recovery & success’. With this property, I revealed the dimensions of ‘guilt & shame’ through the concept of ‘judgement of self’ and, conversely, through the exploration of the dimension of ‘recovery & success’, the ‘reciprocity’ and, finally, the ‘adaptation’ of the SE-AN status. Furthermore, the exploration of reciprocity discovered a possible improvement in the quality of life by the engagement of an aid dog. The interaction between the findings also indicated the maintaining of the cyclic process in the chronic condition. As a result of this, a strong influence and impact of the category ‘one step forward, one step backwards’ is indicated in terms of the quality of life of the women SE-AN sufferers.

Hence, all theoretical codes were underpinned by the initial codings, which led to the theoretical category of ‘one step forward, one step backwards’, and thus, the key findings emerged. Typically, the findings contributed to the body of knowledge of women suffering with the SE-AN condition. In the next chapter, I elaborate on the main category of ‘connective tissue’ by defining its properties and its dimensions.

Chapter 9 ‘Connective tissue’

9.1 Introduction

In this chapter, I present the findings which fall within the category of ‘connective tissue’. The theoretical category of ‘connective tissue’ manages the SE-AN status according to human contact. For example, it provides contact with the ED services, and it also creates personal contacts with other people with EDs. Regarding the previous chapters, I used similar methods to reveal the relevant data, starting with the development of a ‘messy mind map’, in order to define the properties and dimensions of the category. The theoretical category of ‘connective tissue’ emerged as the third category in this study. In accordance with the supervisory team, a metaphoric name was given to this category, which covers the data set which is related to contact and communication with the women SE-AN sufferers. The related study findings are characterised by several components, which explained how people with SE-AN are judged in their interactions in several domains of life.

The people suffering with SE-AN made use of their various experiences by meaning making from the interactions they experienced, and also by defining and justifying their interpretations. These subcategories fostered a number of theoretical findings, which underpin this theoretical category.

In the next section, I elaborate on the theoretical findings which were taken from the interviews, that is, the women’s narratives, and hence, direct quotations are used as in the previous chapter. My continual analysis and interpretation of the data is also woven into the text to illustrate the meaning of the constructs. This creates a robust and grounded approach (Charmaz, 2006, 2008a, 2008b).

9.2 Connective tissue

Initially, in order to gain an insight into the origin of the category, a messy mind map of 'connective tissue' was created (Figure 9.1), which appears below. The model (Figure 9.1) functions as a first categorisation of the findings, and helped me to visualise the several properties. The closely related theoretical findings indicate the relationship with communication *through* the eating disorder.

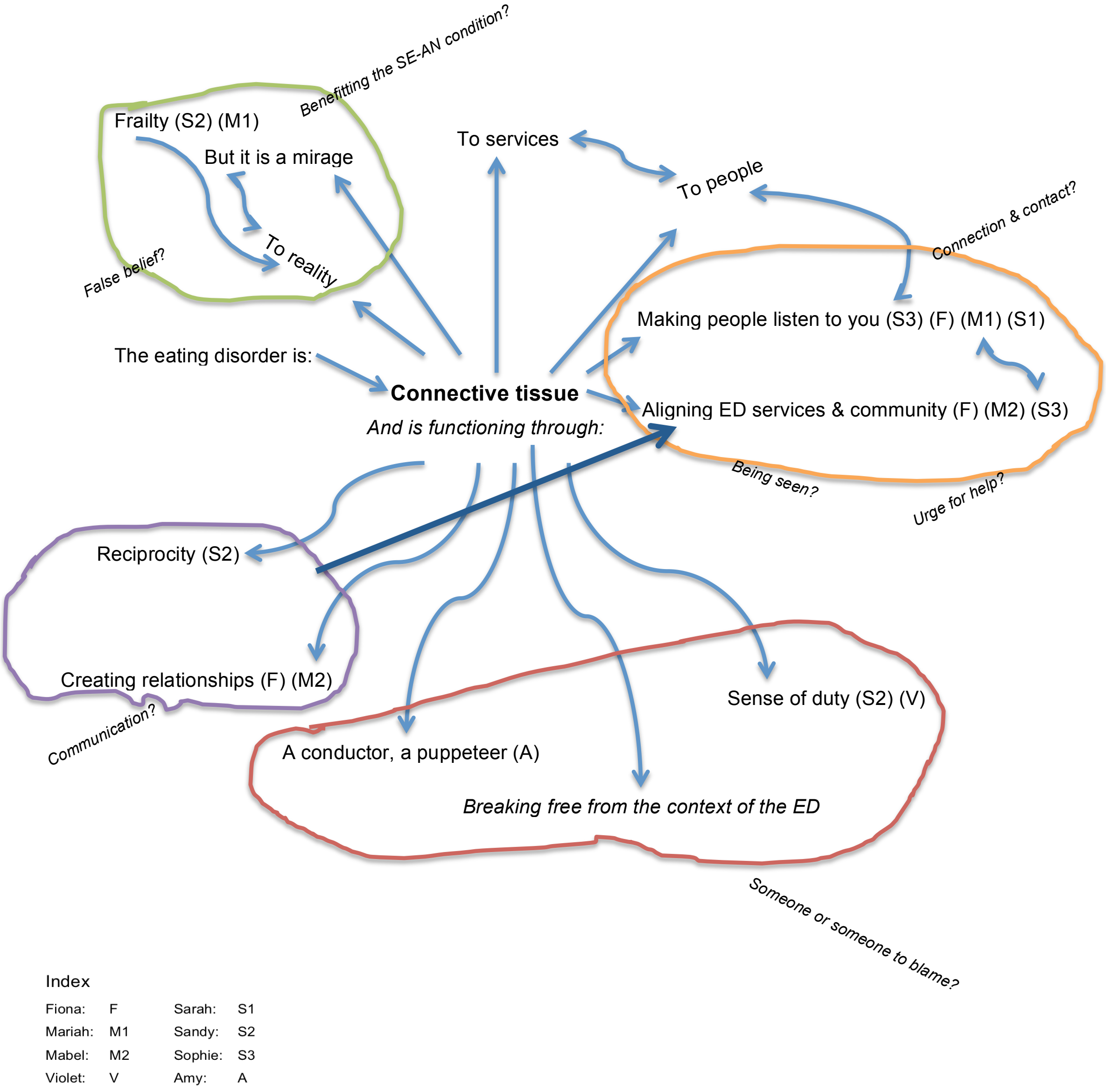


Figure 9.1: Messy mind map of the theoretical category 'Connective Tissue'

As represented in Figure 9.1 above, the theoretical category of 'connective tissue' includes several properties. In the model, I merged the focused codings that were revealed and these are circled by coloured lines. The circles suggest a particular connection between the findings and support the discovery of the properties in the theoretical category of 'connective tissue'. The questions, which are printed in small *italics*, indicated the insertion into the coding family (Glaser, 1978), which I elaborate on in the next section by framing them in a diagram (Figure 9.2). As in the findings of the previous chapters (Chapters 7 and 8), the data was scrutinised in the team meeting[47] to process the theoretical momentum. To apply the dimensions, I have chosen to divide the theoretical category into three properties. The first property is the view to 'maintain within the SE-AN condition' and is surrounded by a **green line** in the model. The second property provides the discovery of 'contact and connection' with other people, and the property is surrounded by a **yellow** line and is underpinned by specific conditions in order to maintain the relationships *through* the eating disorder (**purple line**). In the model, a **navy** arrow suggests a strong relationship, which supports the findings that are connected to 'contacts and connections'. The third property (**red line**) suggests a 'maintenance of the self' within the AN condition. The focused codings, such as 'breaking free', 'living in a mirage' and 'creating relationships', are grounded in the narratives, and function as examples of codings which the main category is built on. Hence, the comparative analysis, which processed the interpretation and adaptation of the interaction, according to the main topic within the lives of the women SE-AN sufferers, identified a number of significant characteristics. This analysis framed the constructs of the SE-AN sufferers as a result of 'the SE-AN patient versus the professional', the SE-AN patient versus their relatives and the SE-AN patients versus other societal dynamics. Furthermore, engagement in human interaction in the context of 'connective tissue' through the AN condition can be interpreted as either 'good' or 'bad' by the women. An example is given below in the following excerpts from Fiona, starting with a positive statement concerning the AN condition and communication:

---

[47] To process the theoretical momentum, similar techniques were used during the 3-day meeting of the supervisory team[47] exploring this category in Section 7.3: 'Suffering, but not in silence' and Section 8.2: 'One step forward, one step backwards'.

> *"I hope that I will be able to deal with my condition, so maybe I can do something with my own experiences."*
>
> (Fiona: L30)

Further in the interview, Fiona stated a more positive aspect of the SE-AN condition:

> *"I have adapted my behaviour and hopefully, in the future, when I am more stabilized, I want to do something with my experiences, and help other people, make a contribution to increase the insights of others in the process of their illness".*
>
> (Fiona: L50)

A few sentences later, Fiona revealed a more negative result of the SE-AN condition, related to contact with others:

> *"I noticed that people think it is too hard to deal with me and my condition. They think it is too heavy, they cannot carry the load of my illness anymore and that is why they avoid me."*
>
> (Fiona: L57)

The first two excerpts (L30; L50) identified Fiona's wish to help others with the experiences she gained in being an SE-AN patient. Her wish is to maintain the societal contacts in the eating disorder community. In the future, she might be able to contribute to prevent other patients from relapse, and she would also like to be able to inform people about the possible consequences of an enduring eating disorder. Fiona wanted to draw on her experiences as someone with a personal understanding of the SE-AN condition. Thus, the constructs put forward, in a positive way, Fiona's wish as to how she could make her illness experiences more useful in contact with others. Within the SE-AN context, Fiona's understanding of the condition might work beneficially and, it is suggested, that the eating disorder behaviours and thoughts could serve as a communicator. The third excerpt implied a more negative aspect of her past experiences, where Fiona suffered rejection because of her condition. However, in the case of the majority of the interviewees, dissonance was detected in dealing with the AN condition in the social world. Thus, on the one hand, the women clearly experienced rejection and have to demonstrate effort to achieve acceptance, but, on the other hand, the women can benefit from the SE-AN condition in their social world. The dissonance between SE-AN sufferers' preferences in their interactions in the social world was further explored through memo writing (see Memo 14 below):

Memo 14: Exploration of the concept of communication

The exploration of communication in the social world in the context of SE-AN offers a superficial picture and, at first sight, it provides no deeper insight into how people with SE-AN engage with social contacts. Besides that, there is no consensus within the group of women. Some concepts were used in the interviews, such as 'using my insights to help other people with ED', 'supporting other people' and 'willing to help people'. Although these codings are important, and underpin the positive view in the concept of communication, it does not explain the more negative experiences of the subject in terms of *how* the women approach other people or, alternatively, *how* the women stay connected in the social world. Moreover, does the contact with ED patients differ compared to non-ED people? What developed a further insight was viewing the concept of communication experiences embedded in the women's interviews. By comparing the data in the context of the narrative, the women's preferences were understood and identified as 'connective tissue' within other theoretical categories. With this, I concluded that exploring the theme of 'connective tissue' is worthwhile in gaining a deeper understanding of the concept of the quality of life in the women SE-AN sufferers.

Memo 14: Exploration of the concept of communication

The memo above provided an insight into the possible ways I had to explore the diversity of communication with the SE-AN women. Returning to the data sets, to realise the meaning in terms of the way of communicating and how the property of 'communication' can best be approached, will help to provide further insight. To gain an overview and to maintain a logical structure to this chapter, in the next section, I present Figure 9.2 which illustrates the properties of 'connective tissue' within the coding family (Glaser, 1978).

9.3 Framing the properties

As previously used in the chapters on the findings (Chapters 7 and 8) to frame the properties, I initially used the coding matrix (Glaser, 1978) (Appendix: 9.2). With this, the important themes referring to 'connective tissue' emerged, and the use of the coding family served as a guide to illustrate the closely-related theoretical findings belonging to the theoretical category of 'connective tissue'. These are presented in the diagram below (Figure 9.2). Box 1 of the diagram reveals the property of 'maintaining the AN condition'. Box 2 reveals the relevance of the 'contacts and connections' for the women SE-AN sufferers, and Box 3 elaborates AN in the role of 'conductor'.

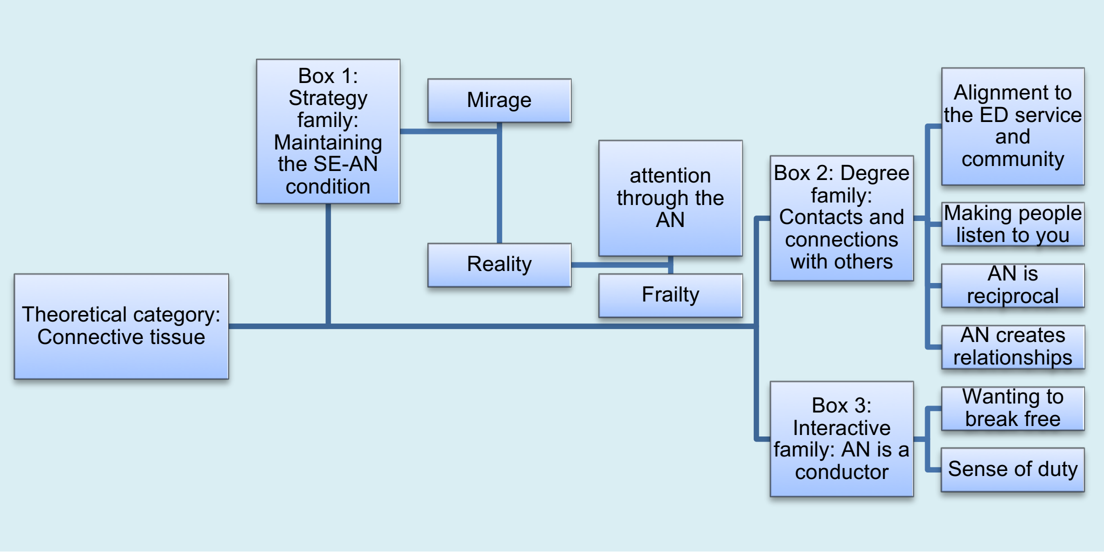


Figure 9.2: Diagramming the theoretical findings within the coding family (after Glaser, 1978).

The diagram above demonstrates a structured overview of the relationships between several properties. The properties are built on the initial codings, which are ‘grounded’ and are found in the interviews. Together, the properties function as evidence for the category of ‘connective tissue’ which emerged. The following section presents the exploration of the properties and the dimensions.

9.4 Exploring properties and dimensions

9.4.1 The first property: ‘maintaining the SE-AN condition’

To build a meaningful concept of the theoretical category of ‘connective tissue’, the first property of ‘maintaining the SE-AN condition’ is detailed in this section. The property highlighted how women SE-AN sufferers relate to today’s reality in terms of their daily functioning. Initially, the early analysis in this project indicated that the behaviour and the convictions related to how people with SE-AN live their lives was significant. For example, the codings, such as ‘eating rules are giving me peace and control’, ‘staying in contact with others through the eating disorder’, ‘I will always be the outsider’, ‘fleeing in the eating disorder’ and ‘living in a mirage’, were the key findings which indicated the daily interactions as influenced by the SE-AN condition. The following excerpts served as examples of such behaviours:

> *"My boss did suffer from an eating disorder in the past. Not specifically the same disorder as I suffer from. And his girlfriend, she also suffered from an eating disorder, so they knew something about the topic, and they told me that it was okay to work over there because they knew I had help. And even more, both supported me with help and understanding."*
>
> (Violet: 87)

And on the question I asked as to how others react to her appearance, Violet's response was as follows:

> *"They told me to wear other clothes and some colleagues wanted to have a personal talk with me. One of them, he is still a friend of mine, told me, you have to go home now and call your daddy, then, he walked with me to my apartment and stayed with me until my dad arrived. And then I went back to my parents' home."*
>
> (Violet: L97)

In the interview, Mariah explained how she experienced the status of being different from others:

> *"On the one hand, it gives satisfaction, like, people notice something about me, but on the other hand, they look at me in a disapproving way, whispering, talking about me to their companions."*
>
> (Mariah: L56)

And Mabel clearly stated that her Anorexia is a safe place in her head:

> *"I have created a safe place in my head and that is the only place where I feel security. But it is the eating disorder's place."*
>
> (Mabel: L76)

Sophie's interview answered the question as to whether her eating behaviours were imposed on her by her eating disorder:

> *"It brings me control. Because, if I do not obey the rules the eating disorder dictates, I feel panic, and fear, or I feel lousy about myself, or bad. Uuuuhm, guilt, uuuuhm, dirt, like, for example, I ate something that I should not allow myself to eat. There are so many mixed feelings. On the one hand, if I admit it, there is a feeling of irritation, and on the other hand, it also gives me peace. That is what it brings me. The feeling of agitation, given by the fact that I have listened to myself is worse than the feeling of, uuuuhm, how shall I say it? - the peace my eating disorder brings me is more bearable and important than the alarm bells I experience once I do not listen to it. The feeling*

> *that comes over me, once I do not commit to the eating disorder, is simply too heavy for me. So, I always surrender."*
>
> (Sophie: L41)

And in the following excerpt, Sophie validated the range of restrictions her eating disorder places on her:

> *"There are always more rules placed on top of the other ones. More exercise, more rules, more things that restrict you, or which you cannot do because of the eating disorder. It became so much more and my body is used to it."*
>
> (Sophie: L51)

In Fiona's excerpt, she explained a sudden attack of the eating disorder and how it influenced her personality:

> *"Suddenly, it attacks you and it has complete power over me, and I lose control of myself. My eating disorder controls my complete life, and my personality."*
>
> (Fiona: L44)

Next, Fiona explained her wish to help people with her experiences as a person with SE-AN:

> *"I have adapted my behaviour, and hopefully, in the future, when I am stabilized, I want to do something with my experiences and help other people, make a contribution to increase the insights of others in the process of their illness."*
>
> (Fiona: L50)

Then, later in the interview, Fiona explored her view on the power of the eating disorder and how she struggled to resist her thoughts:

> *"And the eating disorder tried to convince me to jump into the depth, that I do not want to live like this any longer, the eating disorder battled against my rational thoughts, and as a result, they are rejected because the eating disorder is so much stronger."*
>
> (Fiona: L65)

Sandy's interview referred to the resolving ability of the eating disorder in dealing with emotions:

> *"The eating disorder solves it."*
>
> (Sandy: L80)

And later in the narrative, Sandy described extenuating circumstances to condone the eating disorder:

> *"If you have an eating disorder, or any uncertainness, everybody is addicted to something, though. A lot of people are running away from something. I am more destructive. I know my boundaries in my eating disorder."*
>
> (Sandy: L225)

A few sentences later, Sandy explained her opinion a little bit more:

> *"We are here for each other and we do not search for solutions but we understand each other, and that is, of course, more than okay."*
>
> (Sandy: L229)

Previous excerpts illustrated the reciprocity of AN. Although each of the women experienced a burden in terms of a diminishing QoL, in several areas of their lives, the AN also offered them some comfort in terms of dealing with their emotions, such as those of anxiety, guilt and panic, as referred to in the excerpts from Mabel, Sophie and Sandy. The initial codings, such as 'helping to avoid fear', 'anxiety and guilt', 'defining control' and 'defining peace because of the eating disorder', underpin the property. Furthermore, according to Fiona, a relationship is uncovered, in the contact with other patients, which is controlled by the SE-AN condition. With this, Fiona's 'frailty', which is also a theoretical coding (Figure 9.1), functioned as the connection between the existing contacts in the ED community. As a result, Fiona clearly expresses her wish to volunteer for the ED community, in terms of wanting to establish herself as a 'patient-expert' in the future. The existence of her SE-AN condition provided Fiona with the tools to move on from her current 'dependent patient' position into the situation of being a person who can help others due to her 'personal experiences' skills. Thus, her SE-AN condition gave her the standing *'to be somebody',* and this fits in with her profile of *'being a whole person'*. Thus, Fiona integrated the several roles connected with the SE-AN condition, which validated her position as a person with SE-AN, but as one with a useful purpose.

According to Violet's and Sandy's excerpts, both indulged the SE-AN position within the inner circle of friends. The SE-AN condition, underpinned by their frail appearances, created the necessary attention from other people, and thus, the appearance of the AN condition was noticed by others, which suggested reciprocity, regarding the attention both received with their status. To provide a deeper understanding of this phenomenon, I decided to re-read Sandy's and Violet's interviews. According to Sandy, the only way to achieve attention from her social world was to accept her SE-AN condition and thus to accept her 'frailty'. Without the acceptance of her vulnerable condition, Sandy withdrew from social contact, which led to her completely surrendering to her eating disorder, as referred to the next excerpt:

> *"I was a slave. I was not in charge anymore, I completely lost the power to fight against my illness, and I was afraid of everything. I was so tired, once I got out of my bed, the only thing I did was give attention to my eating disorder habits. I had to eat, vomit, eat, vomit, that was how my days passed then."*
>
> (Sandy: L181)

Thus, by accepting the situation, Sandy was able to handle her social contacts. Nevertheless, at the same time, she devalued the severity of her illness by comparing her condition with the other, more negative, lifestyle habits of other people. Sandy used several thinking strategies. For example, she avoided thinking of the consequences of her SE-AN condition. With this strategy, she experienced her life only 'in the moment', which is plausible for her as it reveals her experience of reality. Thus, for Sandy, the SE-AN condition was one path towards a comfortable position by experiencing the SE-AN condition as an illusion.

Regarding Violet's narrative, the following excerpts referred to her frail appearance compared to the acceptance of the situation, which suggested a certain influence on the communication:

> *"While working in the catering industry, I can mean something to others, it really feels like I mean something to others. Most of the time, I received positive reactions, and sometimes not, but a lot of people want to have a chat with me, or ask questions, but when I see somebody leaving the restaurant satisfied, I am thrilled. It gives me a good feeling about myself, like I really do mean something to somebody. And, when I noticed that what I say is positively effective, that is something that makes me happy. That is why I like to work with people."*
>
> (Violet: L91)

Violet gained internal acceptance of her SE-AN situation through the positive attention she received from others during her work. Nevertheless, Violet succeeded in translating concerned comments from others into a substantially negative opinion that confirmed her idea that she is fat. This implied that such comments are most likely responsible for an increased distance between Violet and her social world. In other words, the opposite effect was achieved. The following excerpt illustrated this finding, when I asked her if she noticed whether other people were watching her:

> *"No, I don't see it, and if I see it, my thoughts are telling me, Oh shoot, they are watching the fat rolls on my back, or, my belly is way too fat."*
>
> (Violet: L156)

This same finding can also be applied to Mariah, who suggested that the SE-AN condition created a type of comfort, which is based on the experiences in her social world. Others noticed that something was going on, in that Mariah experienced both satisfaction and rejection, in terms of how others observed her illness, although she clearly experienced omitted negative reactions with regards to her appearance. Those reactions might be responsible for the cyclic thinking process of a self-fulfilling prophecy[48] or, in other words, her negative self-assessment became the truth, as is illustrated by the next statement:

> *"I haven't got the right to exist."*
>
> (Mariah: L62)

Hence, Mariah's strongly posed statement illustrates the almost tactile degradation of her QoL. In her interview, Mariah gave several examples of her distance from society. This conviction was not only Mariah's personal thought, it was also intertwined into her behaviour. In terms of 'connective tissue', Mariah used both verbal and non-verbal communication in relation to her SE-AN condition in her interactions with other people (L56). Thus, Mariah accepted her reality, whereby the eating disorder offered her comfort in dealing with the condemnation of the eating disorder.

---

[48] Chapter 11: Discussion: Section: 11.2: Discussing the core category: Suffering, but not in silence.

In the explanation of the property ‘maintaining the SE-AN condition’, this revealed the dimensional perspective of ‘reality’, which is underpinned by the initial codings of ‘being frail’ and ‘receiving attention through the AN’. Both initial codings are sustainably related to each other. Hence, on the other side of the perspective, the theoretical coding of ‘living in a mirage’, is seen. Both phenomena are closely related and can be interpreted as forces which constantly influence each other.

In conclusion, the property ‘maintaining the SE-AN condition’ is additional to the understanding of the theoretical category ‘connective tissue’, and includes two dimensions, which are that the eating disorder controls everything, versus the provision of comfort *through* the eating disorder. Both phenomena are directly related to communication in the social world of the women with SE-AN and, in turn, a diminishing quality of life is indicated in the women SE-AN sufferers, through the influences of the maintenance of the SE-AN condition.

9.4.2 The second property: ‘contacts and connections with others’

The analysis of the first property provided an insight into the closely-related second property of the theoretical category ‘connective tissue’. In this section, the second property elaborates on the ‘contacts and connections with others’ within the social world of the women SE-AN sufferers. The dimensions of the property are built on the following focused codings: ‘alignment to the ED service’ and ‘making people listen to you’. To get an appropriate insight into how the property is structured, Table 6 below illustrates the underpinning of the focused codings by the initial codings, which are explained by sifting through sections of data. With this, the data is made grounded. In the table, I highlighted the parts of the texts that corresponded with the focused coding ‘making people listen to you’ in yellow. The parts of the text which are related to the focused coding ‘alignment to the eating disorder services’ is underlined. The reason for utilising these texts marks is because certain constructs can be interpreted by both focused codings, and thus, they overlap with each other. By using this technique, a direct relationship between the constructs and the codings can be seen, and hence, the transparency of the constructivist method is increased.

Table 6: Processing the focused codings by the initial codings

Participant	**Abstracts**	**Initial codings**	**Focused codings**
Sandy: 122-129:	*S: I use to have great plans, I studied, and worked, I was in the train where everybody took place. That's what I wanted. So I have done those things and finally, I couldn't hold on to it, I was graduated, married, a house, mortgage, social life, sports, parties, I've done everything. But, like always, it was too much. I didn't show myself, of what I wanted or needed. I was doing the things everybody did* *I: You were doing the things everybody did, and you felt, uuuuhm, you felt forced to take part in it, when you think about it at the time?* *S: At first I wasn't forced because I like everybody I sat on that train, because it is the picture, made by my parents, by the world, Facebook, you know, I don't know, you'll be part of it. You are not really connected, it wasn't my personal need at all.* *S: And I figured that out the first time and that was really shocking, by the time, I was pregnant… I worked…. The picture was complete, then I thought: Oh, I don't have to work that much anymore. Then I became more and more ill. …. It was more like, now I can say to the world, enough!*	Doing things others expected me to do Surrendering to the ED The ED is functioning as an excuse in no longer meeting expectations Experiencing control because of the ED Saving me from duty The ED is functioning as my buddy	Experiencing a sense of duty Making people listen to you Frailty
Mabel: 46:	*"I don't want the neighbours to know my specific situation. But when people see me, I have to defend myself constantly. About how I feel, how the illness influenced my daily functioning. That is what makes me panic about having of a little bit more food my plate."*	Defending my position as a patient Doing things others expected me to do	Experiencing a sense of duty Making people listen to you
Mabel: 51:	*"The only understanding I receive is from the caregivers and my husband."*	Receiving understanding from caregivers and husband only	Alignment to the eating disorder services Making people listen to you
Mabel: 76:	*"I want to hide myself in my shell. I realize that is a danger, pulling myself back from social contacts, but that is what is going on. I react that way. Because… Yes, they said it in a therapy session, I have created a safe place in my head and that is the only place where I feel secure. But that is the eating disorder's place."*	Benefitting from therapy sessions Avoiding contacts The only safe place is the eating disorder place (in vivo code)	Alignement to the eating disorder services Frailty Making people listen to you
Mabel: 107:	*"I have to wear a plastic corset; I cannot move very well, I cannot move for a longer time. All my joints are always hurting me*	Suffering from the physical SE-AN condition	Alignement to the eating disorder services

	and every time when I get up, my body hurts. My bowels are not working very well. So, this will not make my situation any better. I experience less energy."	Experiencing physical pain The ED is taking all my energy	Frailty

Table 6 enabled an insight into the thinking process regarding the excerpts and the attachment of the initial codings, which led to the theoretical momentum of the focused codings. In order to approach this, I reviewed the data sets again and placed the abstracts in their context. Furthermore, an earlier processed memo (Appendix 10: Memo 17) referred to the analysis of Mabel's data set. The memo was written directly after processing the data set at an earlier stage of the data gathering process, and provided an insight into two main domains:

1.) Mabel used the AN condition in her contact with her husband. A supportive code in this construct is frailty;

2.) Mabel's frail condition has led to her having access to the ED services. With this, the memo appeared as additional to the data and underpinned the theoretical codings that emerged.

The related themes, belonging to the property of 'contacts and connections with others', developed the focused code 'alignment to the eating disorder services'. According to Mabel's excerpts, as illustrated in Table 6 (L51; L76; L107), Mabel's SE-AN condition validated the request for professional help. In this concept, the status of 'frailty', underpinned through the severe physical condition, functioned as an objective validation in order to receive specialised professional care. Hence, the interaction and the co-operation in the focused codings belonging to the properties 'contacts and connections with others' and 'maintaining the SE-AN condition' were demonstrated. Furthermore, in Mabel's constructs, the AN condition is reciprocal, since it offered the possibility of using the SEDU (L51; L76; L107).

Further elaboration of the property led to a deeper understanding of the dimensions. A dimension that was discovered, concerned the following initial coding of 'making people listen to you'. In Sandy's excerpt (L122-129), this phenomenon is related to the severity of her eating disorder. Sandy experienced living her life by the expectations of others that she imposed on herself. Her condition demonstrated Sandy’s boundaries. Thus, in this construct, Sandy’s AN clearly functioned as her voice to speak out loud. In other words, the AN condition is reciprocal, which led to the following conclusion that ‘AN gives Sandy a voice’. Mabel’s excerpts (L76; L107) indicated the direct contact she experienced in her social world, supported by her frail condition which demanded the attention of others. Furthermore, in reviewing Mabel’s complete narrative, this indicated a structural contact with her partner *through* the AN condition (see also Appendix 10: Memo 17). Thus, in referring to the findings, the AN condition appeared to provide a communicator between the parties. Conversely, the ED appeared to be responsible for a decrease in Fiona’s and Amy’s social contacts, as demonstrated in their constructs. Fiona’s next excerpt made reference to this finding:

> *“My eating disorder is the main thing in having fewer social contacts, I am always “busy in my head”, with everything related to eating, I avoid social situations, and contacts which are supposed to be fun, but they are not.”*
>
> (Fiona: L31)

And later in the interview, Fiona emphasized the lack of social contact:

> *“I was a silent person, the only contact I had was with my mom, in those days, for sure, I was very ill.”*
>
> (Fiona: L94)

And a few sentences later, Fiona explained her experiences in making new contacts:

> *“I noticed that I trust more people in the ward. At the beginning, it was difficult, like, how to get connected, but it works. I talk to people I hardly know. Particularly in contact with the nurses, like before, I only wanted to talk with a few of them. But then, a new nurse started working, she gave me the feeling that I was welcome to share my story with her and the other nurses. That was so very important to me. And now, I talk to every nurse, discussing my problems. They are really interested in my story.*
>
> (Fiona: L99)

Regarding Fiona’s excerpts, these indicated the lack of social contact in her life. In Fiona’s constructs, she stated that the ED is counteracting her ability to build friendships, which strengthened her dependence on her contacts with the professionals. However, Fiona is willing, in the future, to use her experience as a 'patient-expert' to increase her social contact, which would, for a start, also motivate her to make new contacts with professionals. Her main purpose, however, is making contacts in her social field. The next excerpts illustrate this point:

> *"I want to do something with my experiences and help other people, make a contribution to increase the insights of others in the process of their illness. I could have done a different kind of study, that is what others wanted me to do, but it is more important, regarding the eating disorder, that I make a contribution to the battle against anorexia."*
>
> (Fiona: L50)

And Amy referred to the broken contact with her father, regarding the influences the eating disorder had on her situation:

> *"For a while, there was no contact between us anymore, because, when we met, there was always something which gave me a lot of tension, and it always ended up badly for me. So I chose to have no contact at all."*
>
> (Amy: L71)

The exploration of the excerpts gained a further insight into the complexity of contact making and maintaining connections for the women SE-AN sufferers as influenced by the SE-AN condition. As Fiona stated, her avoidance of social contact is underpinned by the vulnerable condition caused by the ED (L31; L94). Conversely, Fiona stated her remarkable demand for social contact *because* of her ED condition (L50). Regarding Amy's construct (L71), she stated that the break up with her father was due to his non-acceptance of the ED behaviours. Thus, in this construct, her eating disorder appeared as 'the director' and, as a major consequence of it, the widening of the gap between her and her father. Overall, the constructs indicated the negative influence of SE-AN within the women's communication.

As the next step in the data analysis, the axial coding developed the insights into the dimensions and the several codings belonging to the property 'contacts and connections', which made the findings coherent and interwoven. According to Glaser (1978) and Strauss & Corbin (1990), the axial coding has proved its value in the explanation of the relationships between the categories and the properties, whereby the axial coding gives meaning to the social actions. At this stage of the study, the process of axial coding was administered to demonstrate the relationships within the theoretical findings and it categorised them in several dimensions, such as context, conditions and strategies which made the technique useful in terms of defining the property. Figure 9.3 details the dimensions of the property:

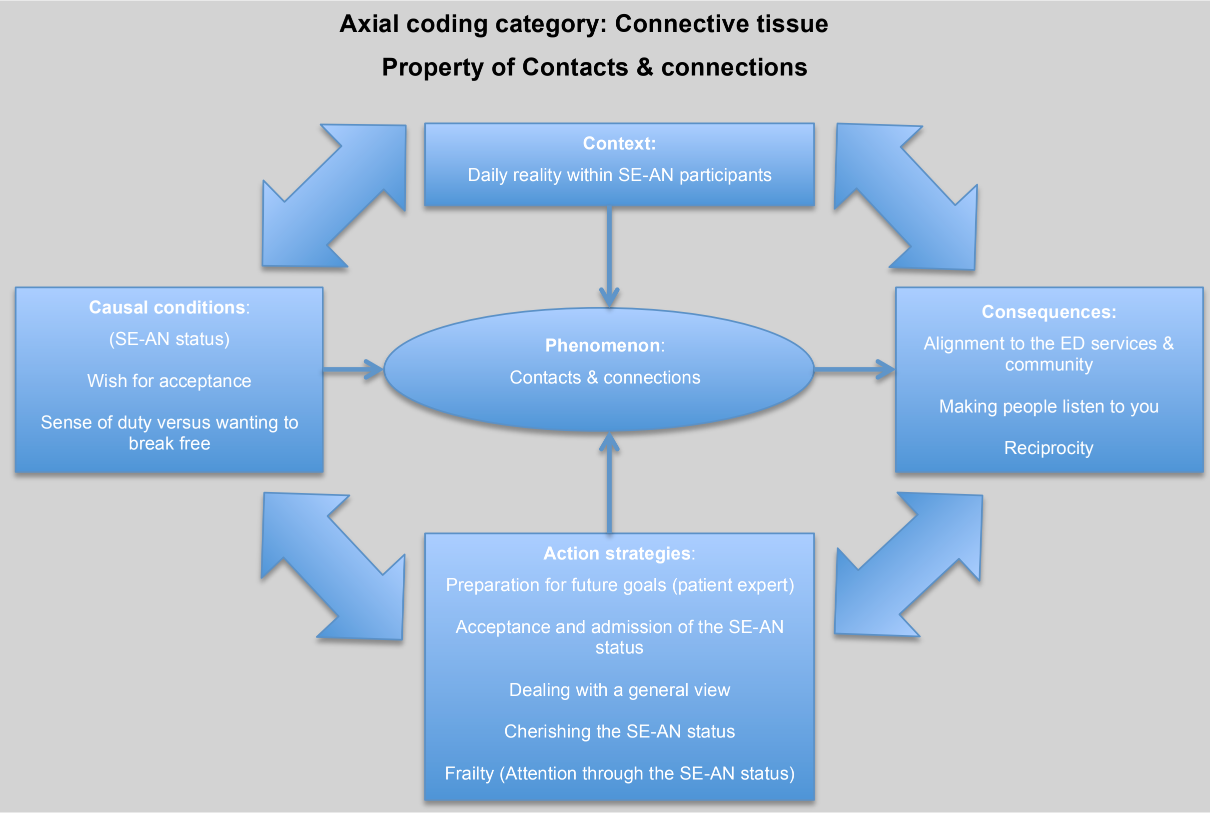


Figure 9 3: Axial coding diagram of the property ‘contacts and connections’

Figure 9.3 explained the dimension of the property ‘contacts and connections’. In the model, the separate dimensions suggest a co-relation with each other, and together they formalise the property. Hence, the consequences, which are included, are seen in the behaviour of the women SE-AN sufferers. Regarding the dimension of the causal conditions, two factors are found in the data which support the conditions. The left-hand arrow at the bottom suggests a tension between the action strategies and the conditions, and it contains a mixture of beliefs, behaviours and wishes that the women experience. Hence, the strategies, which are implemented through the women, lead to the consequences, which are typically *‘to be noticed’,* not only by the professionals, as in their eating disorder sub-community, but also in their social world. However, the actions in the communication can be counterproductive, due to the influences of the ED practices on the women's behaviour and thoughts, which has been caused by earlier experiences, and is referred to in the narratives by the women SE-AN sufferers. Furthermore, the axial coding diagram clarified the overlap of the properties by sharing a similar theoretical code as the underpinning of the diverse properties belonging to the main theoretical category. For instance, it has been found that the theoretical code 'frailty' supports the underpinning of the first property, 'maintaining the SE-AN condition', but this also functions as a significant underpinning to the second property 'contacts and communication', as demonstrated in Figure 9.3.

In conclusion, the findings of the property 'contacts & connections' contributed to, and acknowledged the body of knowledge, in reference to the women SE-AN sufferers. Through the data processing and with regards to the communication difficulties for the women with SE-AN, certain difficulties emerged, which have a significant influence on the experience of the women's quality of life.

9.4.3 The third property: 'the AN is a conductor'

In the explanation of the theoretical category, the third property, 'the AN as a conductor', was explored. During the 3-day meeting with the supervisory team, the title of the property was suggested by consensus. Hence, Charmaz (2006; 2008b) stated to stay close to the text, for this reason, I used the exact words of the women in the titles of the properties. The property is directly related to an excerpt from Amy, which is given below:

> *"I have written a poem, it is called "The Puppeteer", I feel like a puppet, held up on strings, like I am tight up on the eating disorder. I would like to cut though the strings, so that I am able to determine my life. But, at the moment, the puppeteer holds all the strings tightly, he is in the lead. He determines my behaviour, and of course, I am in his power."*
>
> (Amy: L102)

To gain a deeper understanding of the data related to this property, the constructs of the women with SE-AN were reviewed, the initial findings relating to the property were uncovered and the relationship was revealed with regards to the focused coding ‘experiencing a sense of duty’. Likewise, it also revealed the focused coding ‘wanting to break free’. The excerpts from Sandy, Amy, Mabel, and Sophie included the code. Similarly, as with the previous property, Table 7 below illustrates the process of placing sections of texts into initial codings, and then again, into focused codings, which provide the substantial underpinning for the property. In the table, I use the colours yellow and pink to highlight relevant texts. Using two colours was necessary, as the data itself did not reveal the overlaps.

Table 7: Processing focused codings by initial codings

Participant	**Abstracts**	**Initial codings**	**Focused codings**
Sandy: 122-129:	*S: I use to have great plans, I studied, and worked, I was in the train where everybody took place.* *That’s what I wanted. So I have done those things and finally, I couldn’t hold on to it, I was graduated, married, a house, mortgage, social life, sports, parties, I’ve done everything.* *But, like always, it was too much. I didn’t show myself, of what I wanted or needed. I was doing the things everybody did* *I: You were doing the things everybody did, and you felt, uuuuhm, you felt forced to take part in it, when you think about it at the time?* *S: At first I wasn’t forced because I like everybody I sat on that train, because it is the picture, made by my parents, by the world, Facebook, you know, I don’t know, you ‘ll be a part of it, You are not really connected, it wasn’t my personal need at all.* *S: And I figured that out the first time and that was really shocking, by the time, I was pregnant… I worked…. The picture was complete, then I thought: Oh, I don’t have to work that much anymore. Then I became more and more ill. …. It was more like, now I can say to the world; enough!*	Doing things others expected me to do Surrendering to the ED The ED is functioning as an excuse in no longer meeting of expectations Experiencing control because of the ED Saving me from duty The ED is functioning as my buddy Experiencing pressure from the social world	Experiencing a sense of duty Making people listen to you Frailty Wanting to break free
Mabel: 38:	*“I have to do things at home, like cleaning exercising, it is like, constantly being* *active, be strong, never allow myself to* *take some rest, even if I am so tired. And final* *allow myself to eat something;* *I can award myself to eat something.”*	Earning some rest Earning myself some food Keeping the ED quiet: Work!	Experiencing a sense of duty

		Punishing myself by not eating Hurting myself with cleaning and exercises	
Mabel: 46:	*“I don’t want the neighbours to know of my spe situation. But when people see me, I have to defend myself constantly. About how I feel, how the illness influenced my c functioning. That is what makes me panic by a little bit more food on my plate.”*	Defending my position as a patient Doing things others expected me to do	Experiencing a sense of duty Making people listen to you
Sophie: 33:	*“If I take a look at my urge to do physical exerci really do not want to act that way, and the thoughts bothering my eating pattern, the rules, the restrictions. It is not what I am. Moreover, it is the opposite of what I am. That, plus all the time I have to put into my eating disorder, so I will not be able to do things anymore I really like to do. I haven’t got the time and the energy left. So, I became somebody whose life is dictated by the eating disorder, and the current life I live is not what I really want, how I really am. So, it is not that I am completely faded away, but I think half of me is gone, or at least, life has been taken over.”*	Not managing my time Eating rules are giving me peace and control The ED is influencing my whole day My personality is fading away	Experiencing a sense of duty Frailty Wanting to break free
Sophie: 47:	*“I noticed, the longer you are ill, the harder it will be, the tougher the eating rules became. Once, after my first treatment, I had to do exercise on daily basis but there was a maximum of half an hour per day. It was not so much comparing to my current daily exercise. I would give anything now if I could do that again. And of course, I was not recovered but it has been never that anymore”.*	Always panicking on food Empowering the ED Experiencing growing pressure from the ED	Experiencing a sense of duty Frailty Wanting to break free
Amy: 110:	*“It is like I am in a theatre, on stage, you know, the scaffolds all the way up, above the stage? Where the lights are? I have the feeling that the eating disorder is all the way there and determines what I have to do on stage. And, uuuhm, to stay close tc poem, if I remember it well, uuuhm, yes, my fami the public, they have to watch the tragedy of my l*	Empowering the ED Personalising the ED Forced involvement of my family	Wanting to break free Making people listen to you
Amy: 113-114:	*“He rules the play. Yes, he takes care of the tragedy and he also tie my family and loved ones, he forces them to watch the play about my life, and I am completely powerless.”*	Personalising the ED Experiencing guilt against parents	Wanting to break free Making people listen to you
Amy: 122	*“The strings are so tied up, that is why he directs everything, even if I want to do something else. I am exhausted, too weak.”*	Personalising the ED Feeling exhausted	Wanting to break free Making people listen to you

Table 7 illustrates the processing of the theoretical momentum, where sections of texts are understood as the initial codings, which, in turn, led to the focused codings. As shown in the table above, the text highlighted in yellow suggested the relationship with the focused coding 'wanting to break free'. The texts highlighted in pink are related to the opposite code 'experiencing a sense of duty'. Sandy (L122-129), Mabel (L38; L46) and Sophie (L33; L47) experienced a strong sense of duty when referring to the performance of several tasks, for instance, domestic tasks and tasks they were obliged to do, which are imposed by the eating disorder, such as walking and exercising. Sandy gave a clear description of the self-imposed requirements, which, in her opinion, were related to a successful life. In illustration of this phenomenon, Sandy used the metaphor of 'a train', whereby the train represents a journey and human beings have to take part in that journey, which finally leads to human success. However, Sandy experienced her reality by following the demands of the earlier-created obligations which she created herself, for example, her perfectionism, and which was influenced by her experiences in the social world, given by education and in contact with other people. Thus, in Sandy's construct, the findings referred to the context of her SE-AN condition, which are nourished by her persisting beliefs, which existed for a longer period of time and is related to 'experiencing a sense of duty', whereby isolation is indicated. Next, Mabel's (L38; L46) and Sophie's (L33; L47) constructs revealed the experience of the 'the sense of duty' on a daily basis, though both 'fractured' in several of those duties, which functioned as a coping mechanism of their AN. Sophie elaborated on the pressure she experienced from the AN condition, referring to her mandatory daily exercise, which increased during the on-going process. In Sophie's interview, the increased length of time and the intensity of the exercise was observed. Counteraction to this provided physical resistance, growth of anxiety and psychological stress, such as guilt. Thus, both women experienced physical and psychological signals of repulsion, although they are not able to resist the demands which were formulated by their AN. In their situations, the AN is considered to be the 'conductor', and thus, isolation is exhibited. According to Amy's excerpts, in her construct she stated the importance of the empowerment of her AN. Amy was not able to resist to it, and therefore, she experienced an increased degree of suffering which led to her wish of ‘breaking free’ (L110; L113; L122). In this construct, Amy communicated her demand through her family, as if it was their direct wish to stop the suffering of their family member. Amy implied that she is not able to influence her personal AN situation. In this sense, Amy clearly stated that the AN acted as a ‘conductor’, which was a powerful force, that was out of her reach, when she referred to the metaphor of the puppeteer. Furthermore, this finding also implied the interaction with another theoretical coding which belongs to the second property, the theoretical code ‘making people listen to you’, and which functions as the underpinning of ‘contacts and connections’. In this way, the interactional relationship between the properties is demonstrated. (see also Figure 9.4: Axial coding diagram of the property ‘contacts and connections’, in the previous section).

In conclusion, through the exploration of the property, in terms of ‘the AN is a conductor’, the constructs revealed the key findings referring to ‘obey’ versus the wish to ‘break free’ from the SE-AN. A continual tension between the key findings is suggested, and the constructs indicated a significant impact on the social communication and functioning which is caused by isolation.

9.5 Summary

In conclusion, in this chapter, the theoretical category of ‘connective tissue’ was explored, whereby the ‘communication’ through the AN condition to human contact’ of the women SE-AN sufferers emerged. With this, three core categories were revealed. These core categories are: *‘Maintaining the SE-AN condition’, ‘Contacts and connections with others’*, and finally, the *‘AN is a conductor’*. The communication difficulties which emerged are caused by the obedience to the AN, as well as the wish to break free of it. The constant comparative analysis also enables findings to emerge which were aligned to the specified categories. The grounding and analysis of the properties identified a complex two-dimensional relationship regarding other people in the patient's social world, the relatives, the healthcare workers, versus the interfering relationship with the AN self. The reality in which the women SE-AN sufferers live creates a fragile balance in maintaining the values of the relationships with both other people *and* with the AN.

As a result, the first property elaborated on the 'maintaining the SE-AN condition'. In this property, the findings demonstrated a subtle interaction with the women in order that they could stay in contact with others *through* the SE-AN condition, by means of living in their created reality. The second property explored the 'contacts and connections with others'. In this way, the findings referring to this dimension demonstrated that the AN condition provided the women with their contacts. Nevertheless, the opposite was observed, in that, in societal contacts, elimination appeared because of the SE-AN condition, whereby a diminishing quality of life is indicated. In general, the second property underpinned the phenomenon of 'to be noticed', and thus, it can be counterproductive because of the influences the ED practices have on behaviour and thought. The third property explored the field of the 'AN is a conductor'. As seen through the lens of the women, the property identified the interfering power of the continual AN condition, and how the women attempted to create a distance from it. Nevertheless, this property disclosed common opposites, whereby the women experienced a certain force from the AN condition. Nevertheless, the women demonstrated dependence, whereby a diminishing quality of life is indicated.

With these key findings, a deeper understanding of the phenomena referring to the theoretical category of 'Connective tissue' was gained. Hence, I recognised from the key findings that there was a significant impact on the quality of life experienced by SE-AN sufferers. In the next chapter, I elaborate on the fourth theoretical category of 'Best friend, best enemy', by defining its properties and its dimensions.

Chapter 10 ‘Best friend, best enemy’

10.1 Introduction

In this chapter, I present the findings of the fourth theoretical category, ‘best friend, best enemy’. This category recognises the following three core findings, which are: ‘The personification of AN’, ‘Attributing blame’ and ‘Alignment to therapists’. Regarding the previous chapters, 7, 8, and 9, similar methods of data gathering and analysis were used to reveal the relevant findings in the administering of the grounded data.

The theoretical category ‘best friend, best enemy’ emerged as the fourth important domain in this study during the 3-day meeting with the supervisory team in April 2018. The title appeared whilst we (the supervisory team and I) were scrutinising the complete data sets, during the comparison of the interviews of all the women, through the process of constant comparative analysis. Typically, the women SE-AN sufferers recognised the existence of a certain tension in the acceptance of their SE-AN status, as opposed to the perspective of recovery.

In accordance with the previous findings chapters, I start with the development of a ‘messy mind map’ to define and elucidate the properties and the dimensions belonging to this category. Then, the properties and the dimensions will be elaborated on in separate sections, supported by the theoretical and initial codings, which were found in the constructs of the women SE-AN sufferers. To give an insight into the methods used, I provide a clear indication of how the data was reviewed, analysed and how the codings were established. These processes ensured that the categories were formulated through the use of a robust and theoretical process (Charmaz, 2006; Charmaz, 2008).

10.2 Best friend, best enemy

In order to gain an insight into the origin of the category, a messy mind map was created, according to ‘best friend, best enemy’, which is visualised in the illustration below (Figure 10.1). The messy mind map functions as a first catalyst for the emergent findings and illuminates the related properties. The theoretical findings indicate the relationship within the adaptation of the AN condition versus the recovery from AN.

During the continual comparative analysis, it was noticed that the different properties shared the same values, which appeared during the initial coding process. For example, the closely related property ‘guilt & shame versus recovery & success’, belonging to the theoretical category of ‘one step forward, one step backwards’[49], also revealed the underpinning of the delicate balance between the forces which presuppose the maintenance of the eating disorder, and thus, the diminishing quality of life. Scrutinising the data, whilst focusing on the themes, such as ‘fear of losing people’, ‘attributing blame’ and ‘punishing and rewarding’, indicated the significance of this category. Thus, the data that was discovered contributed to the body of knowledge in respect of the women SE-AN sufferers.

---

[49] Chapter 8: One step forward, one step backwards. Section 8.4.2: The exploration and dimensions of the second property

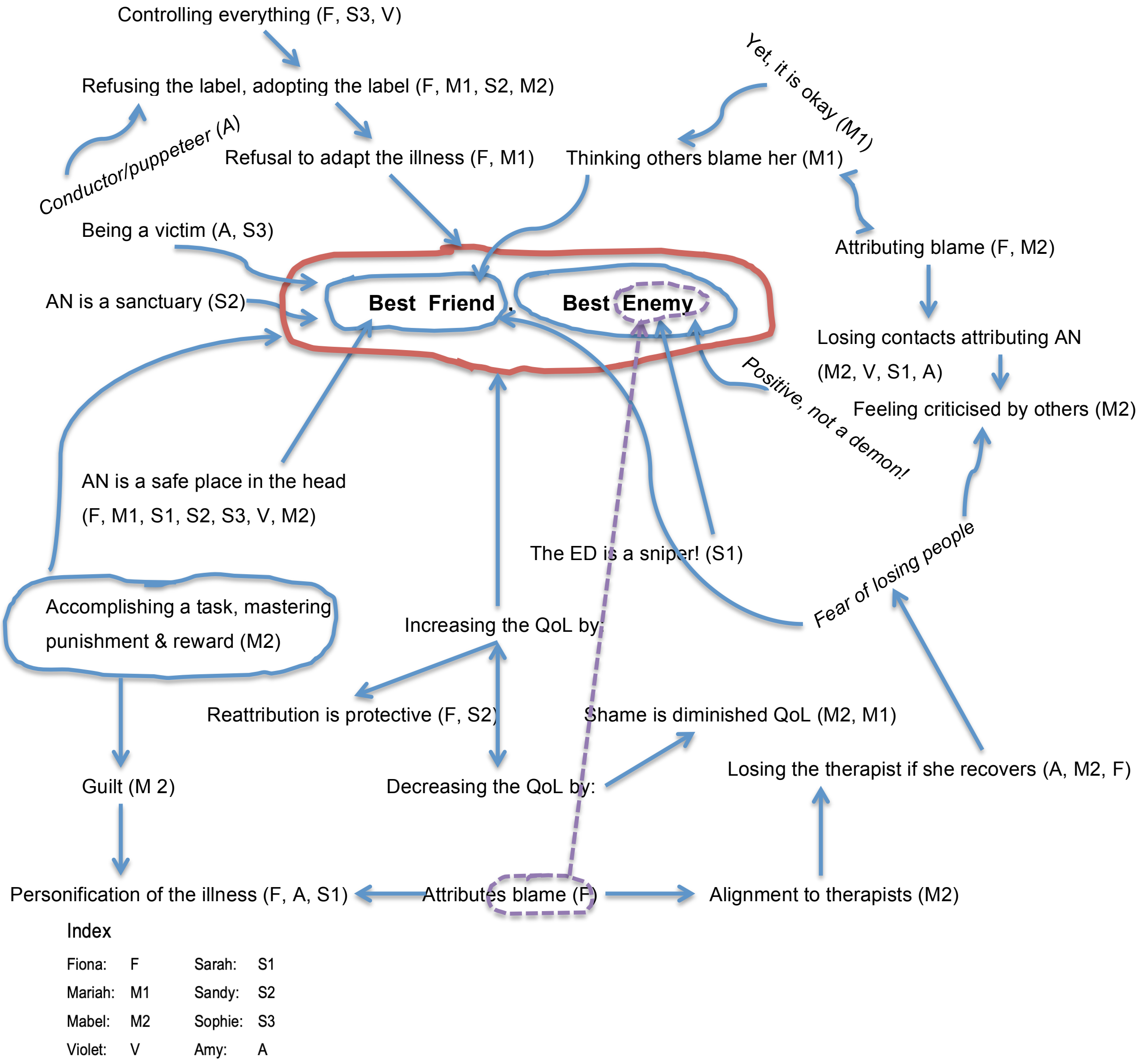


Figure 10.1: Messy mind map of the theoretical category of ‘best friend, best enemy’

In April 2018, a rough version of the mind map was created (Appendix: 7.1), according to the theoretical category determined during the 3-day meeting with the supervisory team. The original mind map functioned as a blueprint for the mind map in Figure 10.1. It elaborated the several properties belonging to the theoretical category of ‘best friend, best enemy’. The data, which was later created during this project, referring to the data sets of Violet, Sophie and Mariah, was incorporated and visualised in the messy mind map as above, by administering the continual comparative method in GT (Glaser & Strauss, 1967; Corbin & Strauss, 2008; Charmaz, 2006; Charmaz, 2008).

In the figure, the theoretical category, ‘best friend, best enemy’, is printed in bold, and the red circle suggests the cohesion within the category itself. Nevertheless, the two inner circles in blue suggest a dichotomy within the category, which is supported by the findings, and is directly related to the sub-category as the connected arrows suggest. The purple dotted inner circle, referring to the sub-category ‘enemy’, is directly connected to the theoretical finding ‘blame’, indicated by the dotted line. Furthermore, as illustrated at the bottom, a continuum is realised. This continuum suggests the tension between the personification of the illness and the alignment to the therapists, with the arrows on both sides of the diagram suggesting a specific relationship within the adjacent theoretical codings.

The comparative analysis, which processed the interpretation and adaptation of the interaction with regards to the theoretical category ‘best friend, best enemy’ in the lives of people with SE-AN, identified the theoretical codings which function as the underpinnings of the category. This analysis framed the women’s constructs as a result of their dynamics in terms of their view on the impact of the SE-AN condition in respect of the QoL as they experienced it.

The engagement, within their personal interactions in the context of ‘best friend, best enemy’ through the AN, can best be interpreted in a dichotomous spectrum, such as ‘good’ or ‘bad’ and ‘friend’ or ‘enemy’. Such examples are given below, in the following excerpts, starting with Sarah’s ‘in vivo’ code, which can be interpreted as a burden that she experiences:

> *“It is a sniper who approaches me slowly and before I knew it, it was ingrained in my life.”*
>
> (Sarah: L47)

A few sentences later, Sarah explained her choice for breaking the contact with her parents:

> *“I have made a decision, I do not know if there is a need of it, but I do not want to search for it anymore. I do not want to search for that specific kind of emotional and personal contact with my parents, because every time, we reached a certain point of disappointment and incomprehension that is not good for anybody.”*
>
> (Sarah: L51)

In Sandy's construct, she referred to the adaptation of the situation, as if she had surrendered to the AN:

> *"S: I do not feel, how do you call it, selfish, self- interested or neglectful of other people. I live my life.*
> *I: What do you mean by that?*
> *S: People can think of me what they want, I do what I have to do."*
>
> (Sandy: L141-143)

Later, Sandy elaborated on her acceptance of her condition, which revealed the theoretical code of reattribution:

> *"I would like to work on a voluntary basis, I do not want to have a real job anymore, I simply cannot do that anymore. For instance, I would give child yoga lessons, or something like that. I would like to offer some help to people."*
>
> (Sandy: L160)

Then, Fiona's narrative is entwined into the constant cycle of 'repel' and 'attract':

> *"I want to live a normal life so much, but somehow, it is so difficult, and then it seems not reachable for me to get over this situation. I lose confidence in myself."*
>
> (Fiona: L59)

Fiona wanted to make a statement concerning her experience in dealing with opposing forces:

> *"On the one hand, it motivates me, in terms of having to beat the illness, I have to gain weight, or, (correcting herself) instead of 'have to', I 'want to' gain weight, because it gives me so many more possibilities. And on the other hand, it is so difficult, I was never happy in my life, I was always worrying, even when I was a child. Then it is hard to imagine what it is to be healthy and happy."*
>
> (Fiona: L61-62)

Amy referred to the 'victims' the illness has, and in this, she personalised the AN process:

> *"It is one big mess. It is a plague. And the eating disorder goes on and on, even if I do not exist anymore. He will be searching for the next victim."*
>
> (Amy: L208)

Amy then goes on to strongly suggest the idea of not being taken seriously by her GP:

> *"And weight is only a symptom. What the anorexic people eat, it is just a symptom. Caregivers should listen to the patient. That is the most important thing. And for me*

> *this matters. I took the step to visit my GP after 6 years of illness, finally, to talk about my eating habits, that was a big step. But after that, I felt insulted because he said, 'Gosh, you are not that thin.'*
>
> (Amy: L250)

Sophie's construct underpinned the theoretical coding of controlling everything in the context of the SE-AN status:

> *"It brings me control. Because, if I do not obey the rules the eating disorder dictates, I feel panic, and fear, or I feel lousy, or bad. Uuuuhm, guilt, uuuuhm, dirt, like, for example, I ate something that I should not allow myself to eat. It is so much a mixed feeling, on one hand, if I admit it, there is a feeling of irritation, and, on the other hand, it also gives me peace. That is what it brings me. The feeling of agitation, given by the fact that I have listened to myself, is worse than the feeling of, uuuuhm, how shall I say it? ... the peace my eating disorders gives me is more bearable and important than the alarm bells I experience when I do not listen to it. The feeling that comes over me, once I do not commit to the eating disorder, is simply too heavy for me. So, I always surrender."*
>
> (Sophie: L41)

Mabel's excerpt presented her view of the criticism she received from her social world:

> *"M: I get the blame for hurting myself on purpose with this behaviour and it makes me feel so angry about myself.*
> *I: Who are the people that talk to you that way?*
> *M: That is my family, my friends, my former boss, the neighbours, and people who have not got any understanding of psychiatric disorders at all, and also, they cannot deal with it."*
>
> (Mabel: L48-50)

And later in the interview, Mabel noticed the change in herself, a trend towards adaptation….

> *"I now have a greater understanding of others, even others with psychiatric diagnoses. I will never rebuke them or say that it is their own fault."*
>
> (Mabel: L61)

Regarding Mariah's excerpt, she criticised a regular treatment she was prescribed in supporting her to beat the AN:

> *"I simply cannot consider a treatment where they ask me to do things I have to do which I cannot do. I will not agree with such kind of treatment."*

(Mariah: L72)

And further in the interview, Mariah connected the earlier recovery from AN that she had achieved to her declining QoL:

> *"A doctor from the social services considered me as being 100 per cent healthy again, I had to work, and then, all the misery restarted, more anxiety, more panicking, social phobia, eating complaints, the whole package came back."*
>
> (Mariah: L88)

Violet benefitted from the eating disorder, as it turned out to be an effective remedy against the bullying she experienced at school:

> *"V: Firstly, I ate too much, then, I ate nothing at all, and this was also connected to the bullying I experienced at school. Then I lost weight.*
> *I: The people stopped the bullying?*
> *V: At the start, no, after the first in-patient treatment, finally, it stopped."*
>
> (Violet: L146-148)

The excerpts, as presented, illustrate both sides of the AN status as experienced by the women. In this respect, the property can be considered as being dichotomous. Nevertheless, the women clearly recognised the two sides in their perspectives, which made compiling this property challenging. Regarding Sarah's excerpts (L47; L51), she made a strong statement by using the metaphor of a sniper, and therefore, the statement was used as an 'in vivo' code. With this metaphor, Sarah illustrated the sudden attacks of the AN, as though, every assault of the AN surprised her time and time again, whereby she failed to prepare herself against the sudden attack. Sarah subsequently made an agreement with the AN, and in doing this, she gave up the emotional support and the understanding of her parents regarding her SE-AN condition. These findings underpinned the theoretical code of the 'personalisation the ED'.

In Sandy's narrative (L141-143), acceptance was revealed, and with this, Sandy was able to hold on to her opinion of the AN, as if she could make an agreement with her AN. In doing this, she experienced less guilt in terms of people she was closely related to, which finally set her free of having to give an explanation of why she made '*the choice for acceptance of SE-AN'.*

The initial codes ‘stop defending my position’ and ‘defining a future wish; giving yoga lessons to children’ (L160) made the data grounded. This view offered a different perspective, by re-attributing the SE-AN condition, Sandy was able to think about her future again, which implied a clear improvement in her QoL. Furthermore, the acceptance of a life-threatening situation provoked a specific tension within her social world, referring not only to people she is close to but also to the clinicians, the therapists and the GPs. It was fascinating to explore this in a memo (Memo 15), which is given below:

Memo 15: ‘Acceptance of SE-AN’: A choice?
While moving forward on this project, the coding of ‘acceptance of AN status’ occurred, and was revealed in several theoretical categories during the study. Certainly, Sandy clearly stated the acceptance of the situation, whilst Violet diminished a certain form of adaptation by using more obscure terms, for instance, the use of the metaphor of the wish to have more independence (within her SE-AN condition). Although the therapeutic perspective in relation to SE-AN is changing, current treatment programmes do not yet include the notion of acceptance with the severe status of the AN condition. In practice, there is an on-going discussion as to whether SE-AN patients are able to make decisions concerning the course of their condition, and discussions with interested parties, such as relatives, but also with professionals, though the debate becomes more critical if the patient is younger. With this, an assumption is revealed, that the SE-AN patient experiences less self-determination if the patient is in adolescence or in a young adulthood phase. Conversely, SE-AN patients ask for self-determination in the form of the acceptance of their situation by other people. With regards to therapeutic alliances, an important factor for the adaptation of SE-AN is the judgement of the professional, where the professional decides whether or not a person with SE-AN is deemed sufficiently competent. This could be a threat, regarding the request for help, in the opinion of the SE-AN sufferers. In addition to the interviews, an observation was made in the contact I had with a patient. I remembered a statement, “I prefer my eating disorder to my marriage”. And even though this patient declared her love for her husband, nevertheless, he was not able to trade places with her eating disorder. Her explanation was that “my eating disorder will never let me down, it is always loyal to me”. As a nurse therapist, it is my belief that I should treat each person as an individual. Age and life experiences play a role in decision-making regarding the course of the therapy, but this should always be discussed in the context of the possibilities, and therefore, the impossibilities. Furthermore, a keen ethical view should be observed, and the patient should always be involved in this process. With this in mind, shared decision-making is possible, which respects the specific status of acceptance as experienced by the patient.

Memo 15: ‘Acceptance of SE-AN’: A choice?

The memo (Memo 15) explored the concept of acceptance of the SE-AN condition. It indicated how careful consideration of the acceptance of the SE-AN situation should be made. With regards to relevant literature on the topic of acceptance, this insight already exists, although to date, it has not yet been fully explored (Tierney & Fox, 2009; Touyz et al., 2013; Touyz &

Hay, 2015). Thus, with this more limited view and more one-sided discussions, the opinion of the person with SE-AN is less strongly interpreted and upheld. In conclusion, the memo contributed to the empirical finding and the importance of the phenomenon of the acceptance of the SE-AN condition.

Fiona's construct (L61-62) illustrated the cyclic wrestling with opposites, the curative versus the palliative paradigm. Fiona vigorously stated her wish for a healthy and happy life, although it is poignant that, in reality, she did not know how to live a healthy and happy life. The initial codes 'wishing to feel happy' and 'radiating happiness' were both directly linked to her construct. Thus, in this construct, it is suggested that the entwining of opposites is a significant finding. In other words, 'best friend, best enemy' are inextricably linked.

Amy revealed the theoretical code of the 'personification of the ED' in the initial coding of 'being a victim', and this finding is directly linked to her construct (Amy: L208). Then, in the second construct, the fear of losing appropriate help appeared by revealing the opposite, whereby Amy felt insulted by the statement that her GP made. Her GP's statement meant that she did not qualify for appropriate support.

In Sophie's construct, she directly stated the empirical underpinning of 'control' (L41), and furthermore, she focused on maintaining the delicate balance between her personal wishes and those that the eating disorder demanded from her. 'Defining peace because of the ED' is revealed as the empirical underpinning and is closely related to the theoretical code of 'refusing the label, adapting the label'.

Mabel's constructs assumed the attribution of blame and the criticism of others (L48-50), which she interprets as a burden. In order to carry this burden, Mabel adopted a view regarding vulnerable people generally (L61), as a result of which she is not the only person needing care in this society. The initial codes, such as 'receiving disapproval of others', 'judging my ED habits by others', 'the feeling of being watched by others' and 'adopting sympathy for vulnerable people' made the data findings grounded.

Then, with regards to Mariah's excerpts, she made the decision to reject regular treatment for her condition, based on a previous experience (L72). However, after a curative treatment, she did experienced a partial recovery for a period of time. Nevertheless, a doctor declared her situation as being improved, and with this, Mariah experienced a sense of pressure to 'perform' again. As a result, Mariah suffered relapses in multiple areas of her life (L88). Thus, taking off the AN diagnosis has led to a diminishing quality of the life for Mariah. The initial code 'refusing to adapt the diagnosis' is the empirical underpinning in the explanation of the construct.

Finally, Violet clearly stated that the AN functioned as a remedy against other emotional burdens, in that her AN created a safe place in her head, where she experienced the control of everything (L146-148). The theoretical codes, such as 'controlling everything' and 'AN is a safe place in the head', addressed these findings directly.

In the next section, I elaborate on a schematic rendering of the several properties of the theoretical category 'best friend, best enemy', to demonstrate the relationship between the revealed properties. To advance this process, a coding family matrix (Glaser, 1978) was used in the development of the dimensions, and which is represented below (Figure 10.2). The matrix functions as a frame to reveal the important properties and serves as a guide in diagramming the closely related theoretical findings, which are structured and represented in the diagram in the next section:

Coding families	Concepts	Examples
The Six C's	Causes, contexts, contingencies, consequences, conditions	Of the theoretical finding best friend, best enemy: context: contacts in the social world (blame of others), losing social contacts attributing AN, alignment to therapists, condition; sharing the same SE-AN label
Process	Stages, phases, phasings, transitions, passages, careers, chains, sequences	Several stages as if it is a chain reaction: During time, less contacts, the more attribution to the AN, According to attention of others; expressing concerns become expressing criticism,
Degree Family	Extent, level, intensity, range, amount, continuum, statistical average, standard deviation	Intensity: Intensity of fear of losing people, losing therapeutic alignment; highest attainable stage: Sanctuary
Type Family	Types, classes, genres, prototypes, styles, kinds	Types: (On the condition) guilt, blame, control, victim
Strategy Family	Strategies, tactics, techniques, mechanism, management	Strategy: To make it bearable: Attributing blame to master punishment and reward, re-attribution AN to increase the QoL
Interactive Family	Interaction, mutual effects, interdependence, reciprocity, symmetries, rituals	AN creates interdependency to therapists, alignment to the service
Identity-Self Family	Identity, self-image, self-concept self-evaluation, social worth, transformations of self	Creating a personification of the illness, adaptation of the illness
Cutting-point Family	Boundary, critical juncture, cutting point, turning point, point of no return	AN is sanctuary
Cultural Family	Social norms, social values, social beliefs	Social norms: non-acceptance of the SE-AN status, leads to stigma, criticism, losing contacts = less contacts within the social norms
Consensus Family	Contracts, agreements, definitions of the situation, uniformity, conformity, conflict	Compliance: acceptance of the SE-AN condition, indicates adaption, patients 'belong to a group', experience similarity and conformity, sharing the same safe place (in the head) Sharing the same values: rejecting the SE-AN label, adopting the SE-AN label

Figure 10.2: Coding family matrix (after Glaser, 1978)

10.3 Framing the properties

This section elaborates on the properties and the relationships between the several properties, belonging to the category 'best friend, best enemy'. Diagramming them in this way is important for providing an overview, thus making the project more transparent and demonstrating how the steps in the thinking process are organised in a logical way. Overall, this gives a continual insight into the working method and also promotes the rigour of this study (Charmaz, 2006; Charmaz, 2008; Chiovitti & Piran, 2003; Coony, 2011).

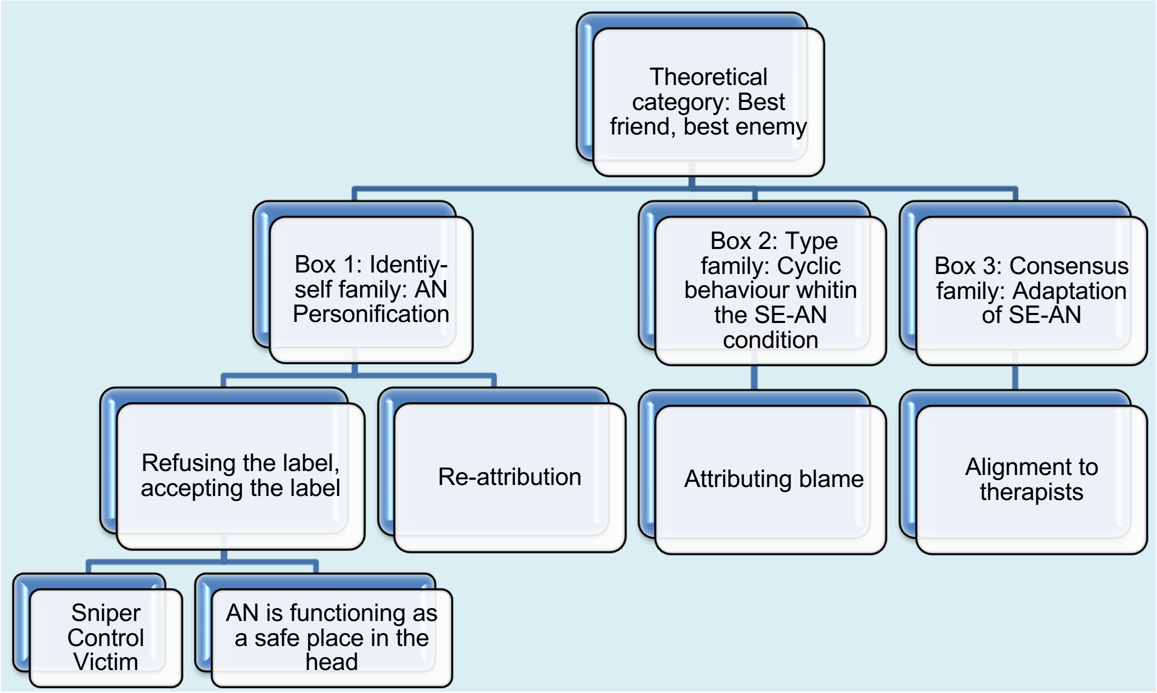


Figure 10.3: Diagramming the properties of the theoretical category ‘best friend, best enemy’

The diagram above demonstrates a structured overview in relationships with the properties that emerged. The properties are built on the theoretical codings, as well as on the initial codings, which make the data grounded. Scrutinising the data provided an insight into the properties that were revealed and developed earlier, and which overlap with other theoretical categories (‘guilt & shame’ and ‘control’). In the exploration of this property, I have chosen to focus on the new findings, such as ‘sniper’, ‘experiencing control through the AN’ and ‘victimising through the AN’, which are findings that support the theoretical code the ‘personification of the SE-AN’, as seen in Box 1. Then, in the perspective of ‘best friend, best enemy’, the theoretical code ‘attributing blame’ is situated in Box 2, which suggests the cyclic behaviour related to the SE-AN condition. Next, ‘alignment to therapists’ supports the adaptation and the acceptance, as proposed in Box 3. Together, the properties function as a support for the theoretical category ‘best friend, best enemy’. A further exploration of the properties reveals the relationship between the properties which refer to the quality of life in women SE-AN sufferers.

In the following section, the exploration of the properties and the dimensions will be revealed, starting with the first property 'the personification of the AN'.

10.4 Exploring properties and dimensions

10.4.1 The first property: 'the personification of AN'

In creating the valuable concept of the theoretical category 'best friend, best enemy', the first property, 'the personification of AN', is detailed. The property endorsed how the women SE-AN sufferers relate to the personification of their illness. The continual comparative analysis indicated the opinions that relate to the personification of the AN. The codings, such as 'puppeteer/conductor', 'being a victim (of what or who?)', 'controlling everything' and 'the ED is a sniper', turned out to be the key findings in the interactions within the women's social world. To find the relevant underpinning of the property, the interviews were re-examined, by means of the search technology, MAXQDA, which supported the search for the appropriate rendering of the relevant data, whilst combining the initial coding diagram findings[50]. The following excerpts provided this theoretical category from empirical evidence, which is embedded in the interviews, starting with the first excerpt from Amy:

> *"A: It is one big mess. It is a plague. And the eating disorder goes on and on, even if I do not exist anymore. He will be searching for the next victim."*
> *I: Do you see it as some kind of a phenomenon that picks up its victims?*
> *A: Yes, a little bit, always looking for vulnerable people."*
>
> (Amy: L208-210)

And in the interview, Amy explained her metaphorical approach to the ED:

---

[50] Figure 6: Diagramming initial codings

> *"I have written a poem, it is called, The Puppeteer, I feel like a puppet, tight on strings, like I am tight on the eating disorder. I would like to cut through the strings, so that I am able to determine my life. But, at the moment the puppeteer holds all the strings tightly, he is in the lead. He determines my behaviour, and of course, I am in his power."*
>
> (Amy: L102)

A few sentences later, Amy proposed the ED as an objectification of a force or a power, which controlled the situation over herself and over her family:

> *"It is like I am in a theatre, on the stage, you know the scaffolds all the way up, above the stage? Where the lights are? I have the feeling that the eating disorder is all the way there and determines what I have to do on the stage. And, uuuuhm, to stay close to my poem, if I remember it well, uuuuhm, yes, my family is the public, they have to watch the tragedy of my life."*
>
> (Amy: L110)

Sarah's excerpt highlights the unpredictability of the ED characteristics:

> *"Of course there was a time that I was really okay, the eating disorder was at the background, but it is a sniper who approaches me slowly, and before I knew it, it is ingrained in my life. A lot of people only know me as the girl with the eating disorder."*
>
> (Sarah: L47)

Later, Sarah illuminates controlling the situation *through* the ED, at the start of her SE-AN condition:

> *"But the focus on eating started then. And in those days, I was slightly underweight but I felt so much control, so it never went out of line because the choice I made of being a sportsperson was too important."*
>
> Sarah: L61)

And in answering my question in terms of the experience of spying, Fiona gave the following explanation:

> *"Suddenly it (eating disorder) attacks you and it has complete power over me, and I lose control of myself. My eating disorder controls my complete life, and my personality."*
>
> (Fiona: L44)

And Mariah described how she approached her situation by means of a mathematical calculation, in respect of how much the ED has taken over her personality:

> *"I cannot be myself, my head is stuffed with all those things. With the psychomotoric therapist, I have made a diagram, the eating disorder proportion in my thoughts is 80 per cent and 20 per cent is Mariah. That is a lot of eating disorder and it is the truth."*
>
> (Mariah: L227)

And Sophie's excerpt expanded on the 'dedication to' versus the 'aversion to' the ED as an entity:

> *"I developed more habits and they have been there for years now. I really cannot imagine if I did not have them anymore, those rules, that they are not with me anymore, or that I will not be able to impose the self-made restrictions anymore. It is so involved in my life. The longer it takes, the scarier it is, and the more difficulties I experience to fight against it. Some of those habits which are with me, are so involved in my personality, but in real time, they are not supposed to. It is not what I am."*
>
> (Sophie: L35)

The excerpts above provided a clear view on the outcomes of the property 'the personification of the AN'. Starting with the exploration of Amy's excerpts, she described the AN in a textual way, in terms of a personification, whereby the AN is a puppeteer, pulling the strings firmly to rule her and her family (L102; L110). An interpretation of Amy's experience that she elaborated on was that the AN is an external entity, and that she experiences that entity as being stronger than herself. This way of thinking, a more negative adaptation of the situation, seemed to relieve Amy from taking responsibility for her situation. In Amy's opinion, the AN is a self-managing system and she experienced being a victim of the controlling interaction the AN executed on her and her family. Initial codings, such as 'not taking the responsibility for the situation', 'losing control', 'losing hope', 'the ED is holding me as a hostage' and 'the ED is a puppeteer' made the data grounded, and thus, empirical.

In accordance with Amy, Sarah also experienced AN as an entity, referring to the 'in vivo' code *'It is a sniper'* (Sarah: L47). Charmaz (2008b) argued that the 'in vivo' codes assist the researcher in distinguishing the meanings of the participants and in explaining their emerging actions. Then, in illustration of 'controlling the situation through the AN', Sarah, who was in the early stages of her condition, experienced this 'control' *through* the AN (L61). At that time, it gave her the focus to be able to achieve her goals in the area of a scholarship for sport at a top level. With this, Sarah seemed to have gathered sufficient evidence that this sense of control can be granted by the AN, thus, the experience of ‘trusting the AN’ might be increased. The AN brought Sarah to a certain level in her career where she was fighting for. The initial codings, such as ‘the lurking ED’, ‘personalising the ED’, ‘defining control’, ‘refusing the label and accepting the label’ and ‘losing control’ made the data grounded. Furthermore, the finding ‘control’ indicated the relationship with ‘the personification of the AN’. Consequently, Fiona experienced the ED as an entity (L44) which suddenly attacks her. With this, she clearly experienced the loss of control over her life and her personality. Meanwhile, the ED took over the control and Fiona felt sidelined. This is in line with Sarah’s constructs, such as ‘control’, ‘the loss of control and the loss of her personality’ and ‘self-determination versus the personification of the AN’, which are all closely related.

Next, in Mariah’s construct, she clarified that the AN controls her 80 per cent of the time, and, moreover, Mariah is convinced of the truth of this statement (L227). With this, it is fitting that Mariah agreed to the personification of the AN. This finding is made grounded by the following initial codings: ‘empowering the ED’, ‘refusing the label, accepting the label’ and ‘my personality is fading away’.

Sophie then developed a more realistic view in her construct regarding the AN as an entity. She experienced her AN as a controlling mechanism and agreed to the experience of the strong involvement her AN directed upon her. Conversely, Sophie held on to the reality that she was not the incarnate AN (L35). The initial codings, such as ‘losing my personality’, ’losing control’, ‘my personality is fading away’, ‘refusing the label, accepting the label’, and finally, ‘experiencing control of the ED’, provided the empirical underpinnings, which made the data grounded. In general, with these findings, the women indicated a strong relationship between the experience of ‘control’ and of ‘personification’. The women experienced losing control, in that the AN is in the lead and also that the women were not able to resist the force that demonstrated itself as ‘control’. In the context of personification, the phenomenon of the AN persecuted on the women, and can be seen as a part of the personification in dealing with the

SE-AN condition. Hence, the control the women SE-AN sufferers experience is a part of the adaptation process with regards to the SE-AN condition.

In the search for the validity of 'sanctuary' as an underpinning of the property, I re-examined Sandy's interview. She explained this aspect in the following excerpt, by answering my question regarding her experience of the difficulties she faced in taking back a more normal daily structure:

> *"Yes, the activity of eating. Also, on the other hand, I am free, because of my illness I can think. What is it all about? So, it is what it is! That I am still standing! Feeling better!"*
>
> (Sandy: L135)

And slightly later, Sandy explained her view on how she adapted her social contacts:

> *"I do not feel myself, how do you call it, selfish, self- interested or willing to neglect other people. I live my life"*
>
> (Sandy; L141)

And in the brief dialogue below, Sandy stated a more philosophical stance in the acceptance of others:

> *"S: People can think of me what they want, I do what I have to do.*
> *I: Is it like that?*
> *S: Yes.*
> *I: So, do you mean, you do not make sacrifices anymore?*
> *S: Yes, I am much closer now, that is good."*
>
> (Sandy: L143-147)

Again, Sandy referred to this same fact:

> *"And I discuss my situation with other people, with 'R' (her husband). I am open about it. Yes, I have noticed that! I can see it!*
> *I: Yes.*
> *S: It is much more deliberated."*
>
> (Sandy: L151-153)

And in this excerpt, Sandy repeated herself:

> *"I maintain my contacts very well but I do things I never did before. I have a cinemovie-card (movie card) from the alternative cinema, so I have a 'cinema friend'. And another friend who also wants to go out to the movies. He lives near the cinema. I also go with*

> *him to see a movie, (murmuring) so, these are more passive things, but it is cozy."*
>
> (Sandy: L241)

Although there is no direct use of the word 'sanctuary', Mariah also held this same view. According to the statement below (L90-94), starting with a question that I had regarding the relationship between the doctor's approval of her restarting her job, versus her relapse:

> *"M: Oh yes, definitely. I had to prove myself, and with that, I needed the eating disorder.*
> *I had to be powerful.*
> *I: So the eating disorder is your strong side?*
> *M: Yes it is. It still is.*
> *I: Your eating disorder helped you to get through that dark period?*
> *M: Yes definitely."*
>
> (Mariah: L90-94)

In Sandy's narrative, with regards to the theoretical coding 'sanctuary', she explained her view on living with the SE-AN status in terms of accepting her situation (L135; L141; L143-147; L151-153). On the one hand, there is her acceptance of the rejection she experienced from other people (L141), and on the other hand, Sandy agreed to a new situation in her life, which is constructed through the lens of her SE-AN (L241). Thus, for Sandy, the AN functioned as 'a safe place in her head', which is a supportive theoretical code. Furthermore, her SE-AN appeared to be responsible for the adaptation of 'low energy activities' (L241), and for keeping non-supportive contacts at a distance (L143-147). The initial codings, such as 'learning to deal with the ED condition', 'looking in my heart for passion', 'experiencing more interests in others on another level', and finally, 'stop defending my position' made the data grounded.

According to Mariah's construct, she also experienced the positive power of the ED, whereby she was able to manage her job (L90-94). This implied the declaration of sainthood of her AN, in that the AN supported her both in difficult situations related to her job and also in other social settings. In this way, the SE-AN condition is responsible for the strengthening of the 'AN sanctuary'. The initial codings, such as 'the ED is giving me a good feeling', 'the ED is giving me the power' and 'experiencing control', are empirical underpinnings, which made the theoretical coding significant and indicated the dimension of the theoretical category 'personification of AN'.

Another important theoretical underpinning of the category is re-attribution in the concept of the SE-AN. In several of Sandy's constructs (L34; L140; L142-146; L150-152; L240), as given above, in the re-attribution of SE-AN, it was indicated that the acceptance of the SE-AN status appeared to be an important factor, and potentially, might work as a protection against the factors which are responsible for the experience of a diminishing QoL. Sandy's re-attribution of the SE-AN condition took account of staying in contact with others and, in addition, it also moderated the feelings of non-acceptance of the self, which implied improved self-esteem.

Fiona's construct also underpinned this finding, and the following excerpt referred to this re-attribution:

> *"I have adapted my behaviour, and hopefully, in the future, when I am stabilized, I want to do something with my experiences and help other people, make a contribution to increase the insights of others in their process of their illness."*
>
> ` (Fiona: L50)

By re-attributing the SE-AN status, Fiona was willing to think that her QoL was improved and, as a result, she discovered re-attribution as an attractive concept to shape her life and to deal with the control the AN has over her (L50). In this way, Fiona mitigated the conditions of her SE-AN. With regards to the diagram of the initial findings[51], 'supporting other people in the future', 'willing to help other people with my insights' and 'experiencing more interests in others on another level', these refer to the constructs which, in turn, contributed to the grounded data. Regarding the theoretical category and the dichotomy included between the properties and the current findings of the 'personification of AN', this mainly supports the 'best friend' principle. The following illustration (Figure 10.4) explains this view:

---

[51] Figure 6: Diagramming initial codings

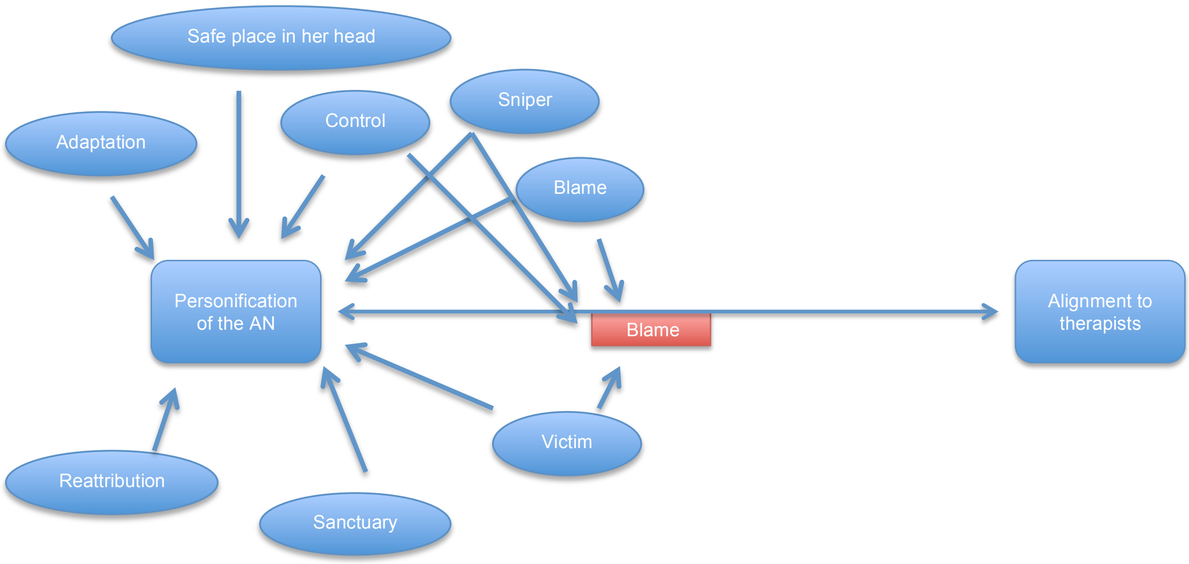


Figure 10.4: Continuum model of the three theoretical codings: personification, blame and therapeutic alignment

The figure (10.4) lists the three properties of this theoretical category:

1) personification of the AN;

2) blame; and

3) the alignment to therapists.

In the explanation of the first property, the 'personification of the AN' was explored, and suggested the representation of the 'best friend' principle. Although supporting the theoretical categories adapt a positive stance with regards to the property, several findings support the negative impact of the AN personification, whereby these findings are more related to the 'best enemy' principle. Regarding the findings in relation to the terms 'sniper', 'victim' and 'blame', all these depict the 'AN personification' and the 'blame' phenomenon. In this way, a strong relationship is indicted between dichotomous findings and the three main properties.

In conclusion, the exploration of the property revealed the core finding of the *'Personification of the AN'*. Furthermore, the relationship between 'control' and the theoretical category 'best friend, best enemy' appeared as significant. The theoretical findings, such as 'being a victim', 'sniper', sanctuary', and the 're-attribution' were supported by the initial findings and functioned as the empirical underpinning of the theoretical codings belonging to the theoretical category. In addition, the 'control' that the women SE-AN sufferers experienced is closely related to 'adaptation', and the possible 'acceptance' of the SE-AN condition. 'Control' functioned as a mitigating circumstance to reach the stage of acceptance in respect of the SE-AN condition. Overall, the finding 'personification' revealed the dichotomous stance with regards to the SE-AN phenomenon, which supported the theoretical category of 'best friend, best enemy'.

The following section explores the dimensions of the second and the third property, 'attributing blame' and 'alignment to therapists', in order to build upon a robust theory. In respect of both properties, I decided to discuss them together, due to the fact that the property 'attributing blame' revealed the final property in this project, 'alignment to therapists'.

10.4.2 The second and third properties: 'attributing blame' and 'alignment to therapists'

The analysis of the previous property provided an insight into the next closely related properties, 'attributing blame' and 'alignment to therapists'. In this section, I chose to elaborate on both properties simultaneously, since they greatly influence each other, and thus are entwined with each other, and by elaborating on 'the blame attribution', the 'alignment to therapists' will also be examined. In this section, I start with the axial coding 'attributing blame' (see Figure 10.5), which contributes to the inductive process of GT (Glaser, 1992; Charmaz, 2006), and the iterative process of the data collection, analysis and comparison (Strauss & Corbin, 1990; 1998, in Vickers, 2016):

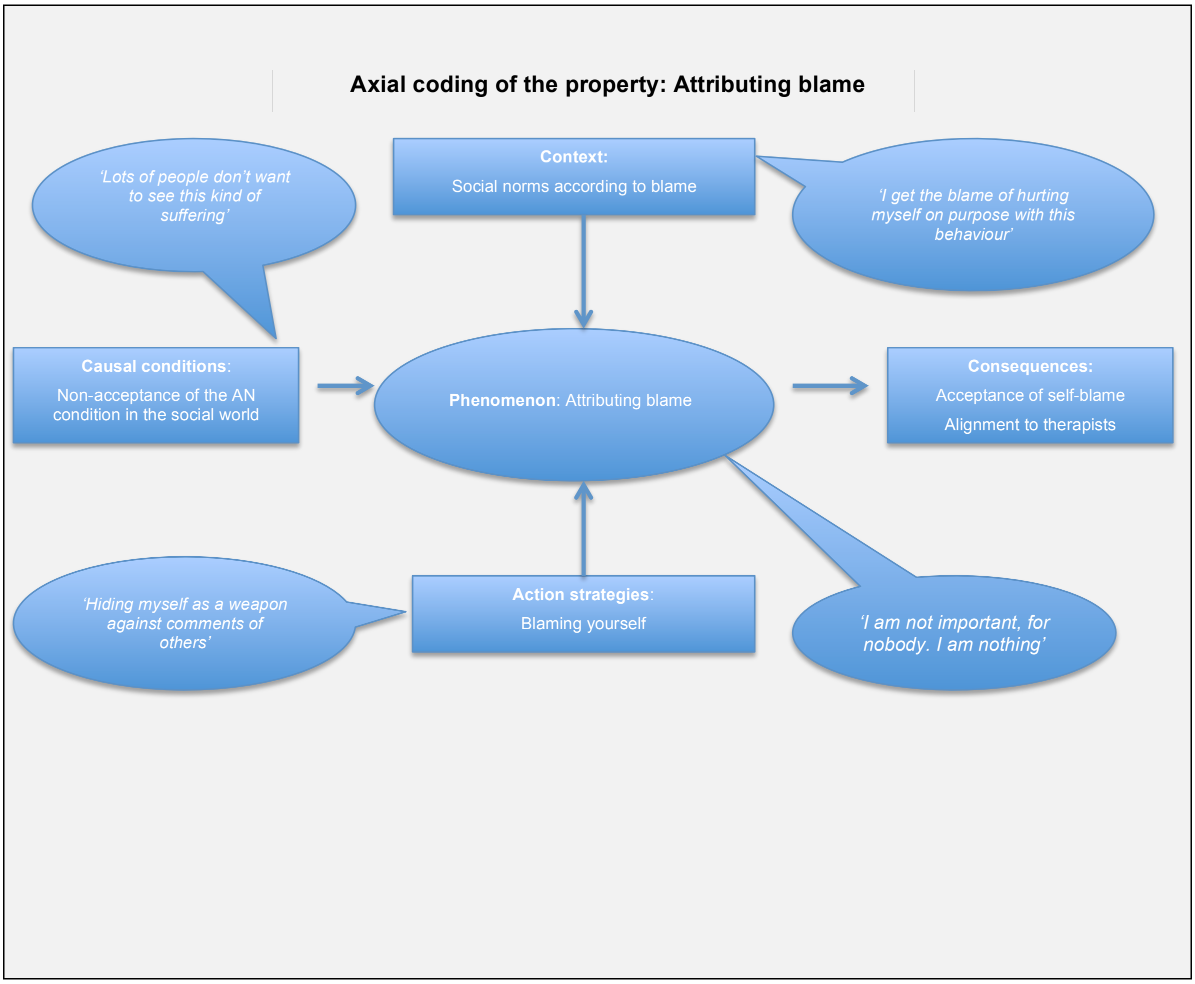


Figure 10.5: Axial coding of the property: Attributing blame

The axial coding diagram, (Figure 10.5) represents a clear insight into the dimension of the property. Each dimension is empirically underpinned by the findings in the women's constructs. Each construct is also represented as an initial coding as seen in Figure 6.3: Diagramming initial codings (Chapter 6: Analysis of data).

In the following section, each dimension of 'attributing blame' was explored. Two women referred directly to the 'blame' experience. As a result, I asked Sophie a direct question concerning the word 'blame' in the context of her reputation. In her answer, Sophie gave a clear explanation regarding the word 'blame':

> *"S: Reputation is more about the fact that I have suffered from it for years now. And I will not succeed in overcoming the eating disorder.*
> *I: Do they blame it on you?*

> *S: Yes. Definitely, yes! According to the media, they always talk about people who overcame their eating disorders, so, "why can't you?", they asked me. "What is wrong with you, why can't you overcome your eating disorder?" "Others can do it, so, why don't you?"*
>
> (Sophie: L 75-77)

Likewise, Mabel is convinced that others blame her for her detrimental behaviour:

> *"M: I get the blame for hurting myself on purpose with this behaviour and it makes me feel so angry about myself.*
> *I: Who are the people that talk to you that way?*
> *M: That is my family, my friends, my former boss, the neighbours, and people who have not got any understanding of psychiatric disorders at all, and also, they cannot deal with the conditions. The only understanding I receive is from the caregivers and my husband. He understands it a little bit. But even then..."*
>
> (Mabel: L48-51)

An 'in vivo' code, *"a person with brain damage because of the Anorexia",* which is embedded in Sophie's construct, as shown below, directed the 'blame' for the painful contact she experienced with her relatives and other social contacts:

> *"As long as people know that I have Anorexia, I see a difference in the way they look at me. Then, there will be judgment and prejudice and a distance right away. And I noticed that, in my direct social environment, they do not see me as the Sophie I was before. I became ill, that was a long time ago. And now, they always treat me as a patient. And still, they treat me as a person with brain damage because of the Anorexia. I know, it is a severe psychiatric disease, but still. Like I am not a 100 per cent anymore. And it annoys me a lot."*
>
> (Sophie: L66)

Sarah's construct referred to a more subtle aspect of blame. She explained about the aspect of condemnation by society:

> *"I feel sadness and anger and also distrust. Sometimes, when I feel better, it seems that the outside world is waiting to see me collapsing again. Like, for how long is she feeling better, when is the next relapse? When will the eating problems start again? And that kind of distrust plays a big role. It hurts me."*
>
> (Sarah: L43)

Topics referring to the lack of attention by therapists were highly relevant for Amy:

> *"I: That is a clear point of view: "Dear therapist, take a look at my personal needs".*
> *A: Yes, for example, what I need is love and personal attention. Yes, maybe other people do not benefit from that kind of help, maybe they need some more practical help. So, there is not one solution, not one size fits all."*
>
> (Amy: L219-220)

And later, Amy elaborated on the concept of blame in the context of an unsuccessful attempt at treatment:

> *"They blamed everything on my parents during the therapeutic sessions with me and my family."*
>
> (Amy: L237)

And in Violet's interview, the experience of blame was revealed in the construct below, where she experienced several emotions, provoked by the 'it is my fault' thoughts:

> *People who directly react, or show intense reactions to me, touch me. Then, I am hurt and sad and angry, because I think it's my fault. I stand in their way. A conclusion, what others think of me influences me very much, and then I hide. I do not want to meet them, I try to avoid them, and that is why I think it is difficult not to cry when they make comments. Because when it touches me personally, it makes me emotional.*
>
> (Violet: L198)

Previously, Fiona blamed herself for being stuck in her situation:

> *"What I said before, as a child, before my illness, I have had other problems, I could not communicate with other people, it felt like a conflict, I always felt like an outsider in groups, I could not be myself."*
>
> (Fiona: L90)

Finally, she experienced relief in giving attention to the phenomenon in conversations with professionals:

> *"Particularly in contact with the nurses, like before, I only wanted to talk with a few of them. But then, a new nurse started working, she gave me the feeling that I was welcome to share my story with her and the other nurses. That was so very important to me. And now, I talk to every nurse, discussing my problems. They are really interested in my story.*
>
> (Fiona: L99)

The excerpts above reveal the relevance and the impact of the second and the third property of ‘attributing blame’ and the ‘alignment to therapists’. With reference to Sophie’s first excerpt (L75-77), this demonstrates that she experienced ‘the load’ of the phenomenon of ‘blame’ that others put on her, in terms of the on-going status of her SE-AN condition. Although nowadays there is more understanding of and attention to eating disorders through social media, as Sophie stated, at this time, there was still a lack of acceptance of SE-AN within society.

This lack of acceptance of SE-AN was realised in the following excerpt from Sophie (L66). With regards to Sophie’s excerpt, Mabel and Violet were also both convinced they would *‘get the blame’*(Mabel: L48) for the situation. In addition to the first statement that Mabel gave, Violet also made the following statement: *‘it is my fault’* (L198), which also refers to ‘getting the blame’.

In order to understand both statements, it was helpful to replace the constructs in the context of the interviews, which led to the following argument: Mabel often experienced rejection and judgement by others, which strengthened her avoidance behaviour with regards to her social contacts. For Mabel, the outside world became a threat, and she therefore developed avoidance behaviour in order to cope with this. This avoidance behaviour was used by Mabel for all her social contacts, except for contact with her husband and her therapists (Mabel: L48-51). This is in accordance with Violet’s constructs, whereby she avoided other people’s opinions in an attempt to avoid criticism. Diverse rejection experiences in her life revealed the strengthening of certain behaviour such as this. Then, regarding Fiona’s construct (L99), she also experienced avoidance by her social contacts. Previously, Fiona lacked any support for her problems, and furthermore, she trained herself to only discuss difficult topics with professionals. Thus, typically, core findings were revealed in respect of receiving attention in terms of ‘blaming the self’ *through* professional contacts, ‘attributing blame’ and ‘alignment to therapists’. Then, in Amy’s construct regarding ‘blame attribution’, she blamed the therapists for not providing the right care, and she accused them of blaming her parents. This finding was also related to the attempt to stay innocent [52] (Amy: L73-75; L64-65) (previously elaborated on in Sections 7.5.1 and 8.4.1). This led to the initial coding, ‘disregarding me’. Other initial codings, such as ‘others are judging my situation’, ‘blaming therapists’, ‘experiencing blame of others’, ‘blaming myself’ and ‘it is my fault’ versus ‘receiving understanding from therapists only’ and ‘sharing her story with the nurses’, all appeared as firm empirical data underpinnings. Consequently, the constructs implied a difference in the blame experience. While Mabel’s, Fiona’s and Violet’s constructs referred to the conviction of blaming themselves, Sarah (L43) and Sophie (L66) blamed other people’s judgment for maintaining their SE-AN condition. Generally, all the constructs referred to the experience of rejection from the community with regards to the SE-AN condition, which suggested a strengthening of the alignment to therapists, and, even though the women did not always feel as though they were understood, the women participants did not feel rejected by the therapists. Moreover, the duration of benefitting from the professional care[53] is of interest, even though the women SE-AN sufferers are not always satisfied with their professional healthcare. The number of years in which one or more professional contact was made available to the women was considerable. Nevertheless, the extant literature argued that less therapeutic help is offered to people SE-AN sufferers, only 50 % of SE-AN people has access to specialised alliances (Goss & Allan, 2009). However, according to the dimension of blame, the findings suggest the opposite. On the one hand, there is a concept of intrinsic blame, driven by the internal condemnation and, on the other hand, there is extrinsic blame, which is related to the judgment of others that the women experience.

To move towards the data analysis with regards to the phenomenon of ‘blame attribution’, it was important to explore the concept in a memo (Memo 16), which is given below:

Memo 16: Attributing blame

---

[52] Section 7.5.1: The exploration and dimensions of the first property, ‘ I will always be the girl with the eating disorder’ and Section 8.4.1: The first property: Innocence.

[53] Table 2: Demographics of the participants

While walking the dogs for a short break during the analysis of the data, two concepts held my attention:
1) Attributing blame; and
2) Guilt.
I asked myself the following question: Are both concepts similar in the context of the women SE-AN sufferers? In the formulation of an appropriate answer to this question, I found that I had to revisit the data sets. By doing this, I placed the findings which were related to 'guilt' and 'blame' attribution in their contexts in order to reach a better understanding of both concepts.
This action appeared to be important in the search for an explanation of the psychological function of the concept.

Hence, revisiting the data brought me the following insights: Guilt refers to the on-going emotion, provoked by *what people with SE-AN do*, bearing in mind the feelings of guilt are inappropriate, since the people suffering from SE-AN have not actually done anything wrong. However, it is their **emotional conviction**. Thus, with this finding, there is an absence of objective situations as to where to place the blame.

Attributing blame in a subjective, one-directional way can be considered as a neurotic defence (Molnos, 1998). Generally, blame attribution stems from insecurity (Molnos, 1998). The one-directional way proposes the following explanation: *Always* attribute blame to others *or always* attribute it to oneself. If people attribute blame to others inappropriately, it is an attempt to avoid taking the blame themselves (Molnos, 1998). This phenomenon is observed in Amy's construct, whereby she blames the therapists and also her parents for her current situation. In Sophie's constructs, she is convinced that her parents blame her for her SE-AN condition.
Attributing self-blame demands from others that they exonerate the self-blaming person. The mechanism of the SE-AN sufferer is their on-going request for redemption from other people.
This supports the *idealised image of the other person*, which is also seen in Mabel's construct, for instance, in the interaction with her therapist and with her husband. Hence, this phenomenon supports the *idealised image of SE-AN*, which is observed in all the constructs of the women SE-AN sufferers. In this way, the finding 'attributing blame' strongly supports the development of the theoretical category, 'best friend, best enemy'.

Memo 16: Attributing blame

The memo (Memo 16) gained an insight into the property 'attributing blame', and clarified a different approach to 'guilt versus blame' in the women SE-AN sufferers' experiences. Furthermore, the memo illustrated the function of the insecure feelings, which are responsible for the blame attribution in the women. Moreover, in the context of the theoretical category, the exploration of blame attribution gave an insight into the dichotomous function within the category, 'best' versus 'enemy'[54]. In the context of the women SE-AN sufferers, the enemy is not approached as 'a demon', and consequently, the AN condition is also connected to a more positive assumption, in respect of an '*idealised image of SE-AN'*. In addition, this finding indicated the personification of the AN (see the exploration of the first property earlier in this chapter, Section 10.4.1).

---

[54] Figure 10: Messy mind map of the theoretical category 'best friend, best enemy'.

Bringing the analysis towards the actual theoretical category, the next step is to clarify the relationship between the properties ‘attributing blame’ and the ‘alignment to therapists’. Therefore, I developed a continuum figure (Figure 10.6) in the extension of the previous continuum figure (Figure 10.4) [55]. In the figure, both properties are underpinned by the initial codings, and disclose the dimensions of the properties.

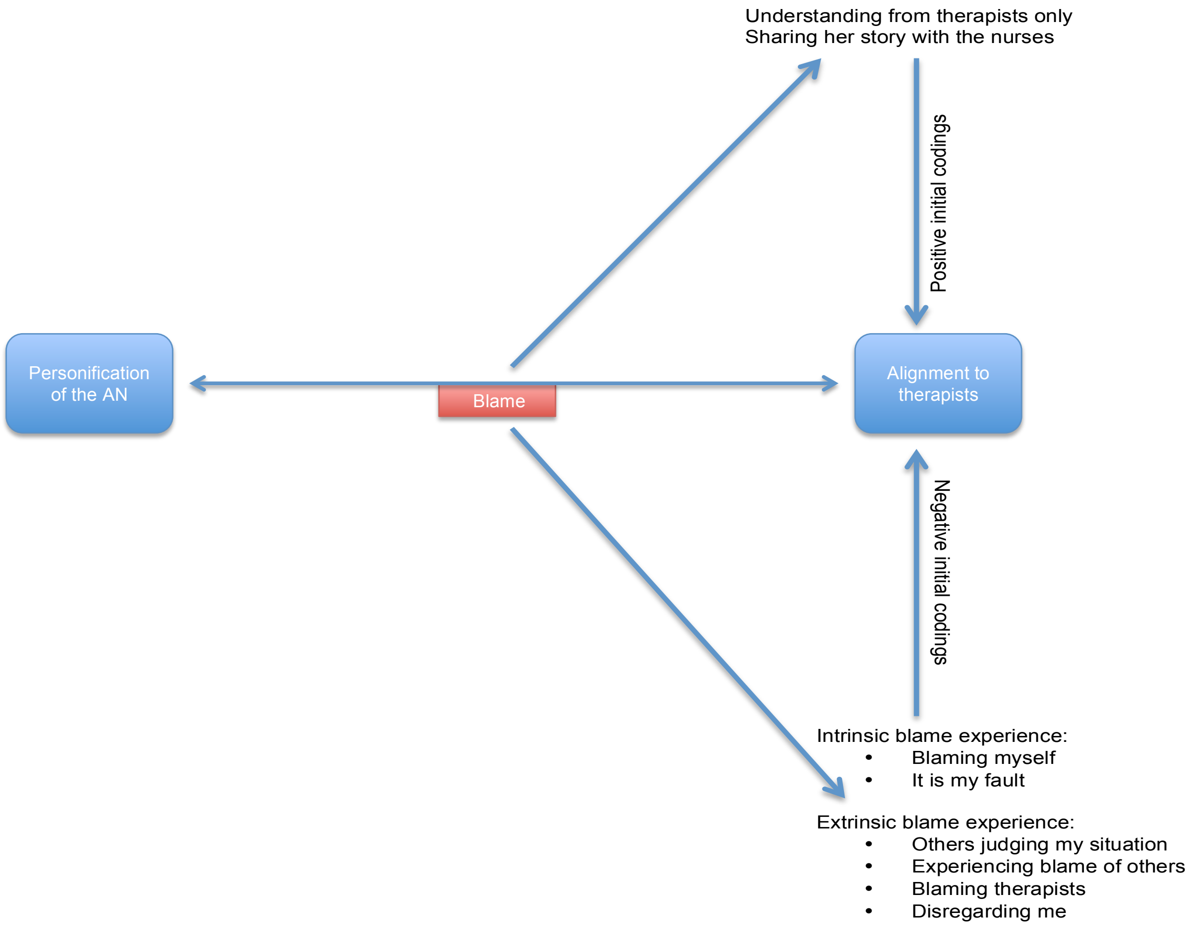


Figure 10.6: Relationship between ‘blame’ and ‘alignment to therapists’

The figure above (Figure 10.6) illuminates the relationship between the ‘blame attribution’ versus the ‘alignment to therapists’. In the figure, the initial codings indicated the exploration of blame, and the codings are divided into two sub-categories, which are the positive and negative experiences with respect to blame. Both experiences give access to therapeutic

---

[55] Figure 10.4: Diagramming the theoretical codings supporting the tension between two properties.

alignment. Hence, focusing on the negative blame attribution experience, subsequently, a dichotomy appeared regarding the intrinsic constructs versus the extrinsic constructs, referring to blame. Subsequently, both factors indicated the strengthening of the personification of the AN.

In conclusion, ‘attributing blame’ and ‘alignment to therapists’, are significant theoretical findings in maintaining the SE-AN status, and thus, the maintenance of a diminishing quality of life. Together, the theoretical findings embody the theoretical category of ‘best friend, best enemy’.

10.5 Summary

In this data analysis chapter, the theoretical category of ‘best friend, best enemy’ was explored, through the operationalisation of three properties, which led to the following key findings: ‘The personification of AN’, ‘Attributing blame’ and the ‘Alignment to therapists’. Firstly, the property of ‘the personification of the AN was discovered and explored. With this, an insight was gained into the relationship between the acceptance of SE-AN, and conversely, maintaining control through the AN condition. Hence, in this property, the delicate balance between both phenomena is pivotal, and thus in its influence on the quality of life experiences. In the exploration of the second and the third property, the following two key findings were revealed: ‘blame attribution’ and ‘alignment to therapists’. Both phenomena are tightly entwined and both function as maintenance for the SE-AN condition, and thus, the status of the quality of life in the women SE-AN sufferers can be seen as the access to the therapeutic alignment. The initial findings, which were discovered in the women’s constructs, made the properties empirically grounded. During the analysis, several methods were used, and the axial coding helped me in defining the dimensions of the properties discovered. Furthermore, through the continual comparative analysis, a dichotomy in the data emerged, and the memo writing served to gain insights into the exploration of the thinking strategies with regards to the project analysis. Finally, the figures which were developed illustrated the insights that were gained and also helped to clarify the thinking strategies. In the next chapter, one cohesive construct will be explained by discussing the key findings from all the developed theoretical categories.

Chapter 11 Discussion

11.1 Introduction

This chapter discusses the findings of the study, and presents the exploration of the twelve key aspects which emerged in the four theoretical categories and which are presented in Chapters 7, 8, 9 and 10. In carrying out this research, I have contributed to a greater understanding of the quality of life in women SE-AN sufferers. This study has created a deeper understanding of the social processes, which occur in those with SE-AN. Furthermore, the chapter informs as to how the women's quality of life is influenced by the SE-AN condition. The study focused on the lives of people who are experiencing SE-AN, thus, in their constructs, their behaviours and thoughts have been revealed, and in this chapter the findings will be compared with already existing knowledge, which has been gained from previous research. The four categories, and their key findings, as identified in previous chapters (Chapters 7, 8, 9 and 10), provide a new step in the understanding of the subtle social processes, within societal interaction, which have shaped the actions of those who experience SE-AN. Furthermore, this study reveals how these actions can be best understood as seen from the perspective of the eight women participants who were recruited from an SEDU of a mental health institution in the Netherlands.

This study aimed to generate an in-depth understanding of the phenomenon, 'the experiences of life', as influenced by the symptoms of severe and enduring Anorexia Nervosa within women. Hence, with regards to the objectives of this study, it was extremely relevant to provide new insights of the life experiences as influenced by the condition of severe and enduring Anorexia Nervosa. Moreover, with the new insights that were achieved, therapists can contribute to the empowerment of people who suffer with SE-AN, and thus it contributes to a deeper understanding of the SE-AN condition, which, in turn, is especially relevant in the empowerment and the support of the women with SE-AN, as well as their relatives and their friends. In this way, an improvement in the quality of life for SE-AN sufferers will be achieved.

To understand the concept of a diminishing quality of life in the women SE-AN sufferers, the study presented four theoretical categories, where all four categories reflected the quality of life experienced by the women. The categories were introduced metaphorically in each of the analysis chapters (Chapters 7, 8, 9 and 10). The metaphors referred directly to the original statements of the women. In the current chapter, the core categories, belonging to the relevant theoretical categories, are discussed in a chronological presentation. Firstly, starting with 'suffering, but not in silence', this category addressed the key findings relating to 'Staying childlike', 'Being seen as a psychiatric patient', the influences on 'Self-image', and finally, relating to 'Addiction'. The second category, 'one step forward, one step backwards', indicated the continual process of illness within the condition, which is characteristic of the chronic condition that is evident in SE-AN, with regards to the experiences of the women and the time continuum of weight loss versus weight gain. Key findings were revealed, such as 'Innocence' and 'Guilt & shame versus recovery & success'. In the third category, I elaborated on the theoretical category 'connective tissue', which covers the major influences of the SE-AN condition in several aspects, with regards to the following key findings: 'Maintaining the SE-AN condition', 'Contacts & connections with others' and the 'AN as a conductor'. Finally, the theoretical category 'best friend, best enemy', was presented and which addressed the following key findings: 'The personification of AN', 'Attributing blame' and 'Alignment to therapists'. In general, all the categories, and thus the key findings, indicated an influence on the quality of life experienced by people who suffer with SE-AN. In the figure (Figure 11.1) below, I illustrate the process of the related theoretical categories. Consequently, the core categories that emerged were examined in conjunction with the extant and relevant literature, in order to compare, defend and place the findings within the development of a grounded theory.

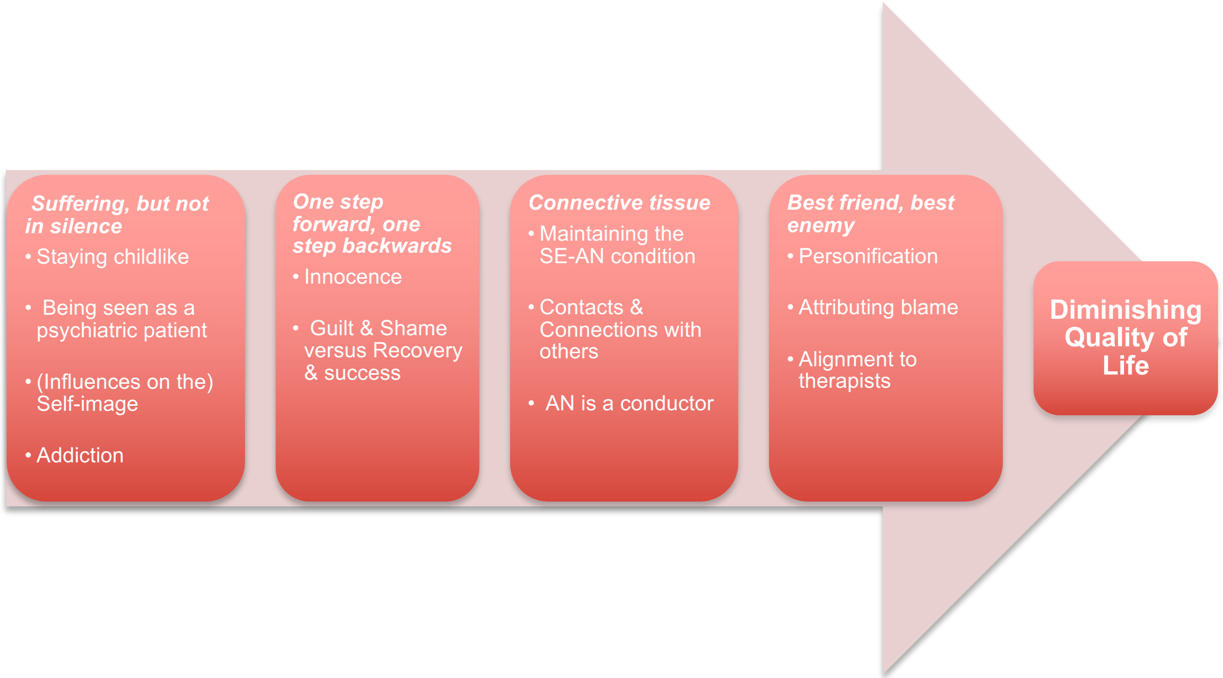


Figure 11.1: Processing the diminishing Quality of Life within SE-AN sufferers

Figure 11.1 demonstrates the insight gained from the building process of the key findings, which emerged during the analysis process, and together, they lead to the development of a diminishing quality of life within SE-AN sufferers. Each separate box indicates the separate key findings belonging to the core categories, which are positioned at the top of the boxes and which are in ***bold** italic* type.

11.2 Discussing the core category: suffering, but not in silence

In this chapter, I start with the elaboration of the most important category that this study considered, because of the strong influence and the interwoven concept of ‘suffering’ within the four categories.

The findings of ‘suffering, but not in silence’ highlighted the SE-AN sufferers’ engagement with their social world, through complex psychological processes, whereby they interpret and give meaning to the interactions. In the exploration of the category, several themes were discovered and were presented in four properties[56]. Together, they identify how the women interact, and how they manage their behaviour in order to stay involved in their social world *through* their SE-AN condition, which indicates a diminishing quality of life. In one of the supportive discussions with my supervisor, the concept of 'self-fulfilling prophecy' appeared, a theory developed by Merton (American sociologist, 1910-2003). A definition of the self-fulfilling prophecy is as follows:

> *"The self-fulfilling prophecy is, in the beginning, a false definition of the situation evoking a new behaviour which makes the originally false conception come true."*
> (Merton, 1948: p.195).

In the context of this study, and in the case of the women participants, a 'fixed' perception of themselves was observed, according to their behaviour and their thinking styles. Hence, their social environment not only expects specific 'fixed' thoughts and behaviour, but it is also likely that their environment reinforces it.

Thus, certain behaviour is characterised by multiple instances of suffering, and the suffering itself is embedded within the four key findings. As a result of this, the suffering functions as a communicator in the social world of the women with SE-AN. The four key findings are given below in Box 1:

---

[56] Section 7.5.1: The exploration and dimensions of the first property: 'I will always be the girl with the eating disorder'.
Section 7.5.2: The second property: 'being seen as a psychiatric patient'.
Section 7.5.3: The third property: 'self image'.
Section 7.5.4: The fourth property: 'addiction'.

Key findings:

Staying childlike

Being seen as a psychiatric patient

Self image

Addiction

Box 1: Key findings of 'Suffering but not in silence'

Thus, as examined in Chapter 7, and as illustrated in Box 1, the category, 'suffering, but not in silence, is built on several forms of suffering, which is of great significance in terms of the quality of life experienced. With regards to the on-going status, underpinned by previous research carried out in the field of SE-AN (see Chapter 2, Section 2.1.5: Severe and Enduring Anorexia Nervosa), this finding suggests that the multiple suffering offers a shelter against the formal request of the social environment, such as family, relatives and professionals, to change their AN status into a more healthier perspective. In other words, women SE-AN sufferers do not want to leave their position of suffering and, if they do, unforeseeable consequences, such as 'taking responsibility', can be induced in all areas of their life. In terms of this study's findings, and in accordance with the literature, the suffering is unambiguous, whereas the path to recovery is not. Instead, the path to recovery evokes resistance, as a result of the previous failure experiences with regards to treatment, which is responsible for demoralizing patients (Touyz & Hay, 2015). Later, some studies advocated a different type of treatment, and thus, a different social paradigm (Tierney & Fox, 2009; Touyz et al., 2013; Touyz & Hay, 2015). Furthermore, Strober (2010), Williams (2010) and Touyz (2013) argued for less focus on full recovery, but more focus on improving the QoL. Sarah's excerpt also underpins this finding, when she makes a statement regarding the continual suffering and the lack of motivation to change:

> *"The quality of life then was the worst ever in my life. I was suffering but I did not want to do something about my situation."*
>
> (Sarah: L59)

And on my question to Amy as to what might be a better quality of life, she answered:

> *"At the moment, it's not that I have to recover totally, but, normally, uuuuhm, normally, it would be nice if I do not have to deal with the eating disorder in my head all day long."*
>
> (Amy: L100)

And in answering my question to Mabel as to whether her eating disorder strengthened the loss of self-confidence and the loss of her quality of life, she replied:

> *"Definitely, and of course, an increase of all the physical complaints that I experience."*
>
> (Mabel: L105)

Then, with regards to the excerpts of Sandy (L232-233, Violet (L229-232), Mariah (L75-76; L151-154), Sophie (L47-48), and Amy (L255-256), the data discovered, revealed the non-pursuing of recovery. With these, the strictness was discovered, which seemed imprisoned in the thinking strategies of the women SE-AN sufferers. Moreover, such findings implied that the women did not wish for full recovery, but they wish for less experience of the ED complaints without abandoning the condition itself. Furthermore, regarding the uncovering of the findings of the four properties, a process arrow (Figure 11.1) is given below:

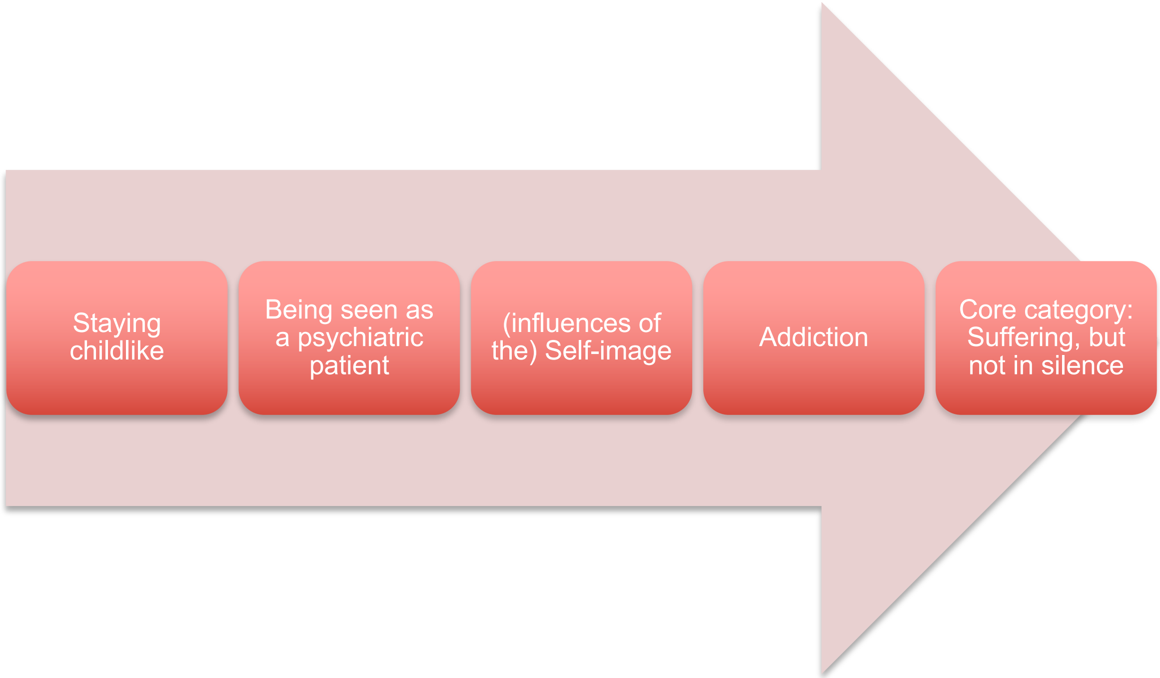


Figure 11.2: Development of the core finding of the first theoretical category

The illustration (Figure 11.1) above suggests the development of the core category which is framed by the SE-AN status in the women. All four separate properties represent a key finding, and together, they lead to the core category of 'suffering, but not in silence'.

In accordance with the philosophical stance of the constructivist approach (Charmaz, 2006; 2008), a relevant literature search is developed, to place, discuss, compare and defend the key findings of this project. With regards to the literature review, I inserted the arguments as to why I accepted, or partially rejected, several sources (Charmaz, 2006: p 163-164) and by using the QARI for assessment, review and synthesising the literature (Hannes, 2010) (see also Section 6.8: The literature review method). To guard the transparency of the study, I added a table of used studies for the literature review with regards to all the core findings of this study, see table 8 below: The overview the studies as used in the literature review. In the table (8) I divided the qualitative, and quantitative studies, the study which can be considered as a 'grey source' (Wessels, 1997), see for further explanation of the concept in the section underneath the table (8), and the literature review studies.

Table 8: The overview of the studies used in the literature review

Title	**Authors &Journal title** **Experiences** **Ethical approval**	**For whom**	**Place**	**Adequacy of participants represented**	**Corresponding study design & methods**	**Corresponding analysis**	**Key findings**
Qualitative research							
1. Severe and Enduring Anorexia Nervosa (SEED-AN): A Qualitative study of Patients with 20 + Years of Anorexia Nervosa	Robinson P.H. et al. (2015) *European Eating Disorders Review* Experienced writer(s): Yes Ethical approval: Yes	(Hospital) policy makers Specialist eating disorder staff members Therapists	Mental Health hospital/ University of London & Ulster, UK	8 male and female adult patient participants	Qualitative research (Charmaz, 2006; Thomas & Harden, 2008) using in depth interviews (4-6 times per patient) duration of 50 minutes each interview	Constructs, open coding, selective coding, constant comparison of findings until theoretical significance emerged	15 key themes determined subdivided in 6 realms. Highest scores are seen in: Severe physical symptoms, psychological comorbidity, social avoidance and isolation and no paid work in occupation
2. A Pilot case Series Using Qualitative and quantitative Methods: Biological, Psychological and Social Outcome in Severe and Enduring Eating disorder (Anorexia Nervosa)	Arkell J & Robinson PH (2008) *International eating Disorders* Experienced writer(s): Yes Ethical approval: Yes	Policymakers of mental health services Therapists	Mental health Centre/ University London, UK	11 male and female patient participants	Mixed Methods	Statistical analysis, comparison of participants with AN with a standardised community sample of participants with depression/ schizophrenia Open coding to determine key themes	The qualitative part of the study (focus on interpersonal avoidance) underpinned poor scores in social relations as revealed in the quantitative method
3. The Meaning of Self-starvation: qualitative Study of Patients' Perception of Anorexia Nervosa	Nordbø R.H.S. et al. (2006) *International journal of Eating Disorders* Experienced writer(s): Yes Ethical approval: Yes	Therapists Screeners	Mental health service/ University, Oslo, Norway Lillehammer, Norway	18 female patient participants	Qualitative design, defined by criteria of data saturation according to Straus & Corbin (1998)	Phenomenological coding and analysed, using QSR-N Vivo software program	8 constructs might have central functions in the maintenance of AN and should be taken in to account when motivation and goals of the patient in treatment are assessed
4. Sense of self and anorexia nervosa: A Grounded theory	Williams et al. (2015) *Psychology and Psychotherapy: Theory, research and Practice*	Therapists Specialist eating disorder staff members	Eating disorders service/hospital/ University London, UK	11 female patient participants	Qualitative research using Grounded theory	Analysis according to the method of Grounded theory by Charmaz	Findings revealed a description of people with AN and their process of their self being taken over by

	Experienced writer(s): Yes Ethical approval: Yes	SE-AN patients					AN and their fear being no one without AN
5. An exploration of perceptions and experiences of living with chronic anorexia nervosa while an inpatient on an Eating Disorders Unit; An interpretative Phenomenological Analysis (IPA) study	Fox & Diab (2015) *Journal of Health Psychology* Experienced writer(s): Yes Ethical approval: Yes	Clinicians Eating disorder professionals	Lancaster, Manchester, University, UK	6 patient participants currently in treatment	Qualitative design, phenomenology	Interpretative Phenomenological Analysis	Findings referred to the discovery of the self which is entwined with the AN what makes it incredibly difficult to perceive a life without AN
6. Eating disorder and the Experience of Self: an interpretative Phenomenal Analysis	Nunn (2009) *Thesis, University of Hertfordshire* Experienced writer(s): yes Ethical approval: Yes	Clinicians, professionals Specialist eating disorder professionals	Hertfordshire University, UK	4 patient participants	Qualitative design phenomenology	Qualitative interpretative Phenomenological approach and analysis	Findings revealed the current views of the self in a relationship with AN
7. An interpretative Phenomenological Study of the Therapeutic Relationship between Women admitted to Eating Disorder services and their care workers.	Wright (2013) *Thesis University of Central Lancashire* Experienced writer(s): Yes Ethical approval: Yes	Clinicians Therapists Specialist eating disorder staff members Eating Disorder patients	University of Central Lancashire University, UK	25 patient participants	Qualitative interpretive phenomenological study	Manual phenomenological coding and analysing & phenomenological coding and analysing, using MAXQDA software program	Findings revealed the exploration of the lived experiences of the relationship between women with anorexia and their care workers in the context of a specialist eating disorder unit
8. Recovery in Anorexia Nervosa: The struggle to develop a new identity	Newell (2007) *Thesis Bournemouth University* Experienced writer(s): No Ethical approval: Yes	Clinicians Therapists Specialist eating disorder staff members Eating Disorder patients	Bournemouth University, UK	12 patient participants	Grounded Theory	Data analysis and interpretation through the conduct of semi-structured interviews and the constant comparison method	Findings revealed that recovery involves the successful integration of four dimensions of recovery
9. Kenmerken en behandelings geschiedenis	Noordenbos et al. (2000) *Tijdschrift voor Psychiatrie*	Clinicians Therapists	Klinische & Gezondheids-psychologie Universiteit	41(former) patient participants	Mixed method, structured questionnaire	Qualitative interpretative data analysis	Findings discovered the negative effects of tube

van patiënten met chronische eetstoornissen.	Experienced writer(s): Yes Ethical approval: Yes	Specialist eating disorder staff members Eating Disorder patients	Leiden, The Netherlands				refeeding, behavioural therapy and hospitalization which develops into distrust in treatment and considering themselves as incurable
10. Treating severe and enduring anorexia nervosa: a randomized controlled trail.	Touyz et al. (2013) *Psychological Magazine* Experienced writer(s): Yes Ethical approval: Yes	Clinicians Therapists Specialist eating disorder staff members Eating Disorder patients	University of Sydney, Australia	63 patient participants	Randomized controlled trail	Quantitative data analysis	Findings revealed that SE-AN patients do respond to, and can benefit from two specialized treatment forms, CBT-E and SSCM. CBT-E.SSCM contributed to improvements regarding health related quality of life and other core comorbidity
11. Recovering Identity from Anorexia Nervosa: Women's Constructions of Their Experiences of Recovery from Anorexia Nervosa Over 10 Years	Conti (2018) *Journal of Constructivist Psychology* Experienced writer(s): Yes Ethical approval: Yes	Policy makers Clinicians Therapists Specialist eating disorder staff members SE-AN patients	Western Sydney University, Penrith, Australia	21 patient participants	Qualitative research, Open interview questions were used to guide in the structure of conversations outside the framework of predominant medical perceptions	Critical discursive analysis, interpretative repertoires and ideological dilemmas were analyzed to reveal the discursive tools women used to construct their identity narratives	Findings revealed that participants rejected the medical discourse of recovery; the women would be remembered instead of being forgotten.
12. The concept of body image disturbance in anorexia nervosa: an empirical inquiry utilizing patients' subjective experiences	Espeset (2011) *Eating Disorders* Experienced writer(s): No Ethical approval: Yes	Clinicians Therapists Specialist eating disorder staff members SE-AN patients	University of Oslo, Norway	32 women participants diagnosed with AN	Grounded theory	Data gathering and exploration of narratives through a two-phase design: 1-open exploratory study, 2-focused study,	The findings suggest that body image is a dynamic phenomenon that may fluctuate in different situations. The body image is also linked to uncertainty about their real appearance.
13. Not my fault: Genetics, stigma and personal responsibility for women with eating disorders	Easter (2012) *Social Science & Medicine* Experienced writer(s): Unknown	Clinicians Therapists Specialist eating disorder staff members	Institute for Genome Sciences & Policy, Duke University, USA	50 patient participants	Grounded theory study	Qualitative interpretative approach by using semi-structured interview method and data	Results reveal novel aspects of stigma from genetic essentialism related to eating disorders

	Ethical approval: Yes					analysis through open en focused coding, and taxonomy-creation	
15. Living with the anorexic voice: a thematic analysis	Tierney & Fox (2010) *Psychology Psychotherapy* Experienced writer(s): Yes Ethical approval: Yes	Clinicians Therapists Specialist eating disorder staff members ED patients	University of Manchester, UK	21 participants from self-help organisations	Qualitative approach	Data gathering through thematically analysis of poems, reflections letters or a descriptive narrative	Findings revealed that the bond between individuals and their anorexic voice could explain their ambivalence to change
14. General shame and bodily shame in eating disorders: a 2.5 year longitudinal study.	Troop & Redshaw (2012) *European Eating disorder Review* Experienced writer(s): Unknown Ethical approval: Yes	Clinicians Therapists Specialist eating disorder staff members ED patients	School of psychology, Hertfordshire, UK	55 women (patient) participants	Quantitative study: Usage of a longitudinal panel design	Measurement of eating pathology, depression, general and bodily shame by using quantitative measurement instruments	Results presented that bodily shame uniquely predicted an increase in anorexic symptoms, and bodily shame predicted an increase in the degree of underweight and the misperception of body size and an increase in fear of weight gain
16. Exercise “Addiction” in Anorexia Nervosa: Model Development and Pilot Data	Klein et al. (2004) Experienced writer(s): Yes Ethical approval: Yes	Clinicians Therapists Specialist eating disorder staff members SE-AN patients	Eating disorders Research Clinic, Psychiatric Institute New York, USA	21 patient participants	Quantitative cohort study	Quantitative data gathering and analysis of dependency by using a semi-structured interview instrument, the Substance Dependence Severity Scale (SDSS), modified to measure exercise dependency	The presentation of preliminary research findings within the determination of dependence to exercise could be measured in phenomenology analogous to that exhibited in substance dependence
Grey literature							
Samen sterk op weg naar herstel. Een onderzoek bij Stichting Mission Puppy	Janssen et al. (2017) *Master thesis, not published* Experienced writer(s): No	Policymakers Clinicians Therapists	Hogeschool Utrecht, Utrecht, The Netherlands	8 ED patient participants	Mixed methods research, descriptive is predominantly	Data gathering by the usage of in-depth semi-structured interviews,	Data suggested the support in the recovery of ED patients by using the insertion of an

Nederland naar Assistentiehonden voor mensen met psychische problematiek	Ethical approval: no Permission to perform research was given by the Hogeschool Utrecht	Specialist eating disorder staff members SE-AN patients				participating observation techniques referring the interaction between dog(s) and their owners	assistance dog
Reviews							
1. Resistance to treatment and change in anorexia nervosa: A clinical overview	Abbate-Daga G. et al. (2013) Experienced writer(s): Yes Ethical approval: NA	Clinicians Therapists Specialist eating disorder staff members	Eating Disorder Center for Treatment and Research, Department of Neuroscience, University of Turin, Italy	NA	Literature review	Selected papers haven been grouped into four main thematic areas in the search for a deeper understanding of resistance to change	Findings revealed the resistance to change in anorexia nervosa: Motivation, insight and subjective meaning of the illness could be useful tools to manage the resistance phenomenon
2. Shame, Pride and Eating Disorders	Goss K. & Allan S. (2009) *Clinical Psychology & Psychotherapy* Experienced writer(s): Yes Ethical approval: NA	Therapists Specialist eating disorder staff members SE-AN patients	Coventry Eating disorder Service, Coventry, University of Leicester, UK	NA	Literature review	Selected papers focusing on shame and shame – based responses in eating disorders	The possible role of shame and pride in the onset and maintenance of eating disorders were reviewed.
3. Cognitive remediation in anorexia nervosa and related conditions: a systematic review	Tchanturia et al. (2014) *Eating Disorders Review* Experienced writer(s): Yes Ethical approval: NA	Clinicians Therapists Specialist eating disorder staff members SE-AN patients	King's college London, UK South London and Maudsley NHS Trust eating Disorders National Service, UK, Illia University, Tbilisi, Georgia	NA	Systematic review	Selected papers on evidence for cognitive remediation therapy effectiveness for AN and other disorders (E.G , autism, depression) were gathered and reviewed	Cognitive remediation therapy approaches appeared to be promising in associated improvements in areas of executive functioning and information processing: links are made with AN in considering of future treatment development
4. The Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders	Hay P. et al. (2014) *Australian and New Zealand Journal of Psychiatry* Experienced writer(s): Yes Ethical approval: NA	Clinicians, related healthcare professionals Eating disorder professionals Healthcare policymakers	Hospitals & Eating disorders services & universities Sydney Australia	NA	Combination of best practice, literature review, systematic review, community and stakeholder consultation	Literature review, literature was thoroughly researched by a broad multi-disciplinary task force	Guidelines in treatment of eating disorders, a harm minimisation approach is recommended in treatment of chronic AN

5. A feminist psychotherapeutic approach to working with women who eat compulsively	Heenan, M.C. (2005) *Counselling and Psychotherapy Research* Experienced writer(s): Yes Ethical approval: NA	Clinicians Therapists Eating Disorder patients	University of Bolton, UK	NA	A feminist therapeutic approach	This paper draws on material from the following: Heenan, M.C. (2005) 'Looking in the Fridge for Feelings': The Gendered Psychodynamics of Consumer Culture and Heenan, C. (1996) 'Women, Food & Fat - Too Many Cooks in the Kitchen?'	A view through a feminist lens on women suffering from eating disorders
6. Severe and enduring anorexia nervosa (SE-AN), in the search for a new paradigm	Touyz S. & Hay P. (2015) *Journal of Eating disorders* Experienced writer(s): Yes Ethical approval: Yes	Therapists Healthcare professionals SE-AN patients	Centre for Health Research School of Medicine, University of Western Sydney Sydney Australia	NA	Systematic review of a broad range of studies referring to eating disorders		The article presented a clear view on the current healthcare landscape focusing on the quality of life in the development of an adjusted paradigm in the treatment of people with severe and enduring anorexia nervosa

Firstly, I started by developing the four key findings, which are related to the theoretical category. According to the key finding, 'staying childlike', I searched the literature for evidence, and found that the amount of literature on this topic is limited. In realising this, I was tempted to include various other material, such as material that is only partially empirical, or material that is less robust or certain (Wessels, 1997), which is a possibility when using GT. As Glaser suggests, *"All is data"* (Glaser, 2007: p 2), which is also the view of Charmaz (2006), as long as it contributes to a deeper understanding of the topic of interest, and thus, as long as it contributes to the credibility.

Despite the limited amount of literature on this topic, one prominent piece of phenomenological research was found, carried out by Nordbø et al. (2006), which investigated the meaning of ‘self-starvation’. The findings of this study contributed to a description of ‘childlike behaviour’ as seen through the lens of changes in the identity, which occurred when people lose weight. Their social environment described them as vulnerable, childlike and weak, though the patients themselves valued these changes as positive effects (Nordbø et al., 2006). Later, a considerably older case study of Crisp (1968) was examined, with twin girls as the subjects, and who were both diagnosed with Anorexia Nervosa. This study referred directly to the occurrence of childlike behaviour in mature patients, such as the development of an intense dependence on the staff and other patients. Childlike behaviour, in terms of manners and speech, were also observed (Crisp, 1968). Other research also referred to the strengthening of childlike behaviour in adolescent people diagnosed with Anorexia Nervosa (Marcus & Wiener, 1989) and, although this was discovered in web sources containing non-empirical material (Wessels, 1997; Glaser, 1978), there is an interesting discussion relating to the topic of staying childlike on a pro-Ana site [57]. Nevertheless, these sites are established by people suffering from AN, and they refer to the view that people who visit these sites, cherish the status of the illness. Hence, it alludes to the notion that food restriction, as well as other impulsive behaviours, are associated with self-pride and a positive self-esteem, which can also be related to religion (Goss & Allan, 2009). This subject is developed in the next sections, ‘Being seen as a psychiatric patient’ and ‘Stigma’. Nevertheless, according to the pro-Ana site, people with AN prefer the childlike behaviour to the extent of speaking with a childlike voice, eating baby food and spending time with innocent childlike games and taking part in other childlike fun. Moreover, some people spoke of the calm, sated feeling which is compared to a state of starvation. Others referred to the fear of getting old. One woman argued that she felt like she was seven-years old, and with this, she was able to avoid conflict. Although only a few sources described childlike behaviour, I consider that these perspectives add further insight into the theme of ‘Staying childlike’, which emerged during the analysis of the data. In the answering of the research question, influences on the QoL are indicated, such as childlike

---

[57] https://www.myproana.com/index.php/topic/404087-childlike-behavior/

behaviour, or conversely, being treated as a child, which is less related to the real age of the person. In addition, this is also conducive with feelings of loneliness and the strengthening of dependence, for example, on their relatives.

In the search for literature to underpin the key findings 'Being seen as a psychiatric patient' and 'Stigma', relevant extant literature was found, which contributed to this project's findings, strengthened them and is supportive of the empirical underpinnings of this study (Charmaz 2006; Vickers, 2016). In conducting the literature search, I used several search terms, such as 'psychiatric patient, 'mental illnesses', 'madness' and 'craziness', and in this, I was deliberately influenced by the terms used by the women. Thus, the literature findings referred to the phenomena of stigma and craziness, which also appear in this project.

Initially, the extant literature contributed to the assumption of defining the Anorexia Nervosa patient as a 'psychiatric patient'. To give meaning to the concept of 'madness', I have chosen to explore the concept in the context of the history referring to Anorexia Nervosa. Hepworth (1999) explains the concept of 'madness' in women suffering from Anorexia Nervosa placed in the context of religion in Western-Christian countries in the 12th, 13th and 17th centuries. Subsequently, the work of Hepworth (1999) take account of the changing medical interpretations of starvation in the 19th century and the appearance of the concept of 'madness', during the transition from a religious authority into a more medical one.

The phenomenon of starvation in women in the 12th century was seen in the 'women Saints' (Hepworth, 1999: p 13). Rys (2005) describes the phenomenon of starvation as an ethical issue placed in Christianity to express remorse about sins, and later on, it was the women who dominated this particular form of starvation. Religious women imposed upon themselves the need to participate in the suffering of Christ. These women were called 'Vastenheiligen', which can best be translated as 'holy fastings' or 'Wonder Girls' (Koninklijke Universiteit Leuven, 1992). In considering these 'Wonder Girls', a prevailing social order gradually emerged that these women were using a form of trickery and deception that suggested that they were unwell.

The medical professionals at the time supported this opinion and designated this as hysterical behaviour. Thus, medicalisation ended the era of the ‘Wonder Girls’, whereby it lost the direct attention of doctors (Van Deth & Vandereijcken, 1998; Payet, 2002, in Van Deth, 2018). To give an interpretation of women in relation to religion and madness, Hepworth (1999) refers to the position of religious authority, which was based on the understanding of ‘good and evil’. Plato, (Greek Philosopher and writer, (428/427 or 424/423- 348/347 BC) was perhaps the first philosopher to engage in this philosophical issue. This dichotomous position was also recognised by Descartes (French Philosopher and mathematician, 1596-1650[58]). Although Descartes is considered as the founding father of modern philosophy. He attempted to find the ‘truth’ by doubting observations, which led to the only truth he had found: *‘cogito, ergo sum’* (‘*I think, therefore I am*’). Hence, dualism, in terms of the ‘body’ and the ‘mind’, was also recognised as a philosophical ‘problem’. And given this philosophical stance, ‘the mind versus the matter, the phenomena were approached separately. Descartes deepened this opposing ‘problem’, which is referred to as ‘Cartesian Dualism’[59]. Descartes opposed the position that there was a link between the mind, consciousness and self-consciousness, also known as the ‘I’. According to Descartes, the ‘I’ can be considered as an independent phenomenon of the material world; after all, to achieve a ‘thinking reality’ the material matter, for instance, the ‘human body’, is not needed. Nevertheless, despite the independency of the ‘I’, Descartes considered a human being as a covenant between the body and mind.

As seen from the Dualism perspective, women who were practicing differently from the religious norms were judged as being possessed by evil, and this difference was mainly seen as a threat to the social order. However, earlier religious interpretations considered women who fasted as if they were a higher order. Thus, fasting was seen as only a minor threat, which privileged these women and protected them against witch-hunts. A second point was that

---

[58] https://www.filosofie.nl/rene-descartes/index.html

[59] https://www.allaboutphilosophy.org/cartesian-dualism-faq.htm

witch-hunts were based on the notions of good and evil, and were responsible for the interpretation of the difference between reason and ignorance. The difference between and the categorisation of behaviours was the central dogma in the distinction between ‘normal’ and ‘madness’ (Foucault, 1971, in Hepworth, 1999: p 16). This view was responsible for defining abnormal behaviours, including Anorexia Nervosa.

In general, the literature findings underpin the ever-present dogma of ‘being a psychiatric patient’ which the women experience. This finding is in accordance with the significant findings of this project, although it is also responsible for the strengthening of the stigma, which is examined in the following section.

Regarding the literature specifically related to stigma, Griffiths (2015) points out that the effects of the phenomenon may actually increase self-stigma in people with eating disorders. A systematic review by Puhl et al. (2015) indicates that a ‘weight stigma’ accomplishes a unique influence on core eating pathology and on psychological maladjustment. Furthermore, the stigma promotes social rejection and the increase of negative stereotypes in eating disorder patients (Puhl et al., 2015). In research into people diagnosed with Anorexia Nervosa and Bulimia Nervosa, Griffiths (2015) stated that people who recognised higher levels of core eating disorder psychopathology are often associated with frequent stigmatisation, lower self-esteem, a longer duration of the disorder, and increased self-stigmatisation. The interviewees specifically described the fact that they are convinced that they are ‘personally responsible for their condition’ and that they feel ‘they should be able to pull themselves together’ (Griffiths, 2015). In the study by Easter (2012), it was suggested that people with eating disorders were stereotyped as ‘competent’, which suggests that patients may carry the responsibility regarding their illness. Indeed, this contributes to the notion that people with eating disorders carry the blame and the responsibility, demonstrate weakness, selfishness, and finally, self-destructiveness, which all imply a decline in stigmatisation (Easter, 2012). These conclusions appear to conflict with Stewart’s (2006) findings, where participants recruited from the community believed that the person suffering from Anorexia was best able to pull themselves together, and was most to blame for their situation.

In the processing of the theoretical momentum of the self-image, the extant literature findings were sought. In recent studies, the concept of ‘self-image’ in Anorexia Nervosa has received much attention (Williams et al., 2015; Nunn, 2009; Amianto et al., 2016; Newell, 2007; Conti, 2018). In my project, I consider this phenomenon as an important theoretical underpinning of the main category, ‘suffering but not in silence’, in the search for coherence within the other properties. In respect of the women’s constructs, a relationship between the AN and the self-image is recognised. However, in order to stay within the remit of this project’s research question, I focused on self-image in the context of SE-AN only. In doing so, I was able to compare the grounded findings of this project (Charmaz, 2006). Although the influences of SE-AN on self-image are considered important, this is not a new finding, since it is already acknowledged that there is a relationship between identity and the chronic form of AN (Nunn, 2009; Williams, 2015; Conti, 2018; Wright, 2013). Therefore, in order to stay within the scope of the philosophical stance of this study’s approach, I was drawn towards a study by Charmaz (1990), which examined ‘chronic illness’. Charmaz (1990) studied ‘the self’ in people suffering from a chronic illness, through the lens of a social constructivist grounded theory methodology. In this study, Charmaz (1990) stated that the participants had developed a preference in several identities concerning their conditions. Furthermore, the study argued that the ‘sense of self’ and how others respond to the illness, changed over time in terms of living with a chronic condition (Charmaz, 1990). Likewise, in mental illnesses, and therefore in SE-AN, the self is often affected by the chronic condition that people suffer, which is complicated by the fact that there is a lack of sickness-awareness and insight, in the sense that people with SE-AN do not consider themselves as being ill (Kinderman et al., 2006, in Williams et al., 2015). And although people’s identities change over time, Williams (2015) argued that particularly younger people deny their illness and, it is precisely this argument, which is potentially problematic for Anorexia Nervosa patients. In considering the prevalence of AN, most patients develop their eating disorder during adolescence, at a time when identity is characteristically being formed (Williams et al., 2015). Hence, Williams et al. (2015) argued as to whether AN should be approached as an identity issue or as an illness. According to Williams et al. (2015) the persistent use of the medical model in the investigation of eating disorders, their causes, their prognoses and their treatment was, therefore, challenging, since the medical model did not examine the lived experiences, as followed by the social construction of AN as a phenomenon of the self. In the use of other research models which support the phenomenological aspects, AN can be seen as a protection against problems, and a force to empower SE-AN sufferers in coping with emotional and social problems (Williams et al., 2015). This is also in accordance with a phenomenological study by Nunn (2009). The findings of Nunn's study emphasised the existence of the 'fragile sense of self', which she divided into three sub-themes, based on the responses of the participants in her project. These sub-themes were 'being uncertain about the self', 'negative experiences of the self', and 'the sense of self is subverted by perfectionism and a high level of self-criticism' (Nunn, 2009). A more recent study of the self and Anorexia Nervosa (Amianto et al., 2016) stated that the body experience is not integrated as a part of the self. Although this particular experience is not comparable to schizophrenia, for instance, there is, however, an attitude of 'objectification', as if the body is separate from the person, the 'self' (Amianto et al., 2016). According to Amianto et al.'s (2016) theory, this is consistent with the theories that suggest that physiological responses are the origin of the emotions. Thus, this also indicates that AN patients do not relate the experienced emotions to the self. Generally, the extant literature findings are in accordance with the current findings of this study project, and with this, the findings are considered as empirical underpinnings in this field of study. Furthermore, this strengthened findings which support the notion that the SE-AN condition influences the personality.

The final key finding of the first theoretical category is 'Addiction', which the women SE-AN sufferers clearly state is strongly related to the AN condition. In order to build a robust theory, it was helpful to make a comparison of the findings with already existing literature to defend and strengthen my data. Furthermore, it appeared to be supportive in defining the limitations of the property in an attempt to avoid getting lost in the field of addictive behaviour (Charmaz, 2006). Thus, I decided to include only the studies which are related to both addictive behaviour and eating disorders. This provided a number of insights. Firstly, in a follow-up study, based on the principles of grounded theory amongst women diagnosed with anorexia nervosa, the interviewees found affirmation in the term ‘addiction’. In addition to this finding, they also rejected the term ‘total recovery’. This refers to a non-fit in the framework of addiction as known in psychiatric care (Conti, 2018). In the Conti (2018) study, the participants refused to adopt the term ‘total recovery’, because of the on-going addictive behaviour they experienced after they were considered to be ‘clinically recovered’ (Conti, 2018). As it came to self-destructive, addictive eating behaviour, which is also in accordance with Sandy’s excerpt (L180-183), Conti (2018) allocate the impossibility to intervene, and signals of relapse within patients were not detected by patients themselves (Conti, 2018). In a comparative study with AN and substance abuse, Barbarich-Marchsteller (2011) argues that AN is not an addiction in itself. This statement contradicts Sandy’s construct (L180-183), in that for her, a strong ‘craving’ for bingeing was experienced, and once she had given in to this, there was a sense of relief, followed by a feeling of exhaustion, which is consistent with addictive behaviour.

An earlier study by Klein (2004) stated the correlation between exercise dependence and the level of anxiety suffered. The study described healthy runners, who reported higher levels of euphoria and lack of pain during exercise. Such findings also supported the biological link between excessive exercise and drug abuse (Klein et al., 2004). Moreover, the findings also supported the following statement that exercise provided a significant intervention against the feelings of anxiety (Klein et al., 2004), which made the findings in the study compatible with Sophie’s construct (L108), where she clearly stated how her emotions were suppressed by exercising, which she expressed as ‘hurting herself’, as stated in the following excerpt:

> *“Why I hurt myself? So, I won’t have to deal with emotions. I don’t have to deal with anxiety, fear, and hurt.”*
>
> (Sophie: L108)

Returning to the research question, it is as follows: *Which factors are responsible for a reduced quality of life of persons living with a diagnosis of Severe and Enduring Anorexia Nervosa?* The operationalisation of the fresh findings gained in Chapter 7, and with a view of the prevailing paradigm which mainly focuses on a curative treatment, along with the support of the extant literature findings, this led to the following conclusion, that SE-AN sufferers experience major suffering through the SE-AN condition, and specifically, an in-depth understanding has been gained regarding the topic of childlike behaviour within the SE-AN patients. As a final step in the discussion of the findings, this conclusion provided access to the relevant literature regarding the therapeutic approach to the SE-AN patients. In the most recent edition of the *Dutch Handbook for Eating Disorders* (2018), one chapter by Noordenbos & van Elburg (2018) is dedicated to the ethical issues relating to people with eating disorders. The chapter described the therapeutic approach regarding the legal (in)capacity in people with a serious anorexic condition, although this did not only focus on people suffering from SE-AN (Elzakkers & van Delden, 2018: p 374, in Noordenbos & van Elburg, 2018). However, the chapter did contribute to the issue regarding the ethical aspects concerning the legal (in)capacity of people diagnosed with AN for at least the past 7 years, and thus, the development of chronicity was suggested. As seen from this perspective, according to Elzakkers & van Delden (2018, in Noordenbos & van Elburg, 2018), a tentative proposal is suggested, which is based on a more phenomenological approach, rather than a positivistic one. Moreover, phenomenology suggests the combination of several complementary approaches regarding human science and furthermore, a combined approach addresses the phenomena which cannot be identified separately from each other (Tamboer, 1989, in Cox et al., 2005: p 24-25). With this type of approach, I consider its contribution as important, despite the fact that Tamboer's chapter appears to have been developed specifically for physicians, and in the decision-making, with regards to seriously ill patients, the approach proposes the involvement of all important people in the life of the SE-AN patient, whereas it made good use of the extant literature sources.

In the field of SE-AN, research is not widespread, although some interesting findings have emerged. For example, Strober (2004a, in Grilo & Mitchell, 2010) advocated a different paradigm in the management of SE-AN, referring to the continuing resistance to change and thus the positioning of the on-going suffering. Strober stated that by providing psycho-education in the developmental model of chronicity, and by encouraging patients to establish daily routines in terms of their social contacts and their hobbies, the therapist should then plan regular meetings with the patient's family and other important people in the patient's life to also educate them in the chronicity of the illness and to support them in the acceptance of SE-AN in their loved ones (Strober, 2004a: p 234, in Grilo & Mitchell, 2010). In Strober's (2004) chapter, the professional knowledge according to the target population was suggested, the author can be referred to as an authority in the field of SE-AN, and in addition, the chapter was securely underpinned by several referenced literature sources. Furthermore, suggestions were clearly made in support of the usefulness of daily routines in the treatment of SE-AN patients. Hence, the suggested method served as the theoretical underpinning of the *Dutch Guidelines for Eating Disorders* (Zorgstandaard Eetstoornissen, 2017) and for the *Royal Australian and New Zealand Practice Guidelines* (Hay et al., 2014). In both guidelines, loyalty to the SE-AN patients is described. Thus, with these findings, I concluded that knowledge relating to acceptance and adaptation of the therapies already exists, and despite the existing knowledge, there appears to be inadequate implementation of existing knowledge, and a perceived lack of co-operation and engagement with the SE-AN patients. A rather important finding made the last suggestion a reasonable assumption. Strober (2004a, in Grilo & Mitchell, 2010) described the uncomfortable emotions that therapists felt during contact with patients, for example, where a patient was described as *"rippling beneath the skin"* in the process of a tedious dialogue (Strober, 2004a: p 235, in Grilo & Mitchell, 2010). Moreover, Strober (2004a, in Grilo & Mitchell, 2010) argued that it is not advisable for one therapist to provide therapeutic help for more than a few SE-AN patients, and it is also strongly recommended that the therapist has frequent supervision to protect themselves against possible countertransference with patients, and it is precisely these feelings described by SE-AN patients which unveiled the following finding, that it deprived them of the respect they deserved, which suggested the induced feelings of non-acceptance.

In conclusion, I have considered the extant literature to reflect the rather important findings concerning the phenomenon of ‘suffering’ which appeared in this study. The current findings of this study are strongly related to the existing literature whereby the body of knowledge referring to the quality of life of SE-AN sufferers is strengthened. Hence, the literature search offered a specific approach, and it also highlighted the potential pitfalls of being in contact with SE-AN patients. Nevertheless, according to the details that have emerged in this project, SE-AN sufferers appear not to benefit from the previously developed knowledge of the condition, and it is, therefore, suggested that therapists are not yet aware of the therapeutic approach that these groups of people should be offered. Thus, these study findings can undoubtedly be used to improve therapeutic alliance in health care.

11.3 Discussing the core category: ‘One step forward, one step backwards’

In Chapter 8, I presented the theoretical category of ‘one step forward, one step backwards’, through the analysis of the two revealed properties. An exploration identified a personal and complex societal structure, regarding the women SE-AN sufferers, as visualised in Figure 8.5, which presented a ‘weight continuum’. According to this figure, the cyclically influential relationship between the factors of ‘guilt & shame’, related to the fear of weight gain and weight loss was illustrated, along with the related forces according to weight gain, which represents ‘success’. Through the comparative analysis, the key findings of ‘Innocence’ and ‘Guilt & shame versus recovery & success’, as seen through the lens of the ‘weight gain-weight loss continuum’, emerged. With this, a cyclic process was recognised, wherein a delicate balance between ‘shame versus guilt’ was seen and the maintenance of the ‘fear of weight gain’ emerged.

Typically, the maintenance of the SE-AN condition, and thus a non-recovery 'style' is indicated as a significant finding in the experience of a diminishing quality of life within SE-AN patients. The process arrow below, suggests the relationship between the two properties and, together, they support the theoretical category of 'one step forward, one step backwards'.

Figure 11.3: Development of the core finding of the second theoretical category

The arrow in Figure 11.3 illustrates the key findings that emerged during the analytical process, and which contributed to the core category of 'one step forward, one step backwards'.

The analytical interplay by the constant comparative analysis revealed several core eating disorder convictions. Through the lens of the weight gain-weight loss continuum, the key findings 'Innocence' and 'Guilt & shame versus recovery & success' emerged. Box 2 below represents these key findings.

Key findings:

Innocence

Guilt & Shame versus Recovery & Success

Box 2: Key findings of 'One step backward, one step forwards'

In this section, I define, place, defend and compare the current findings with the existing literature in the processing of the theoretical momentum, which contributes to this GT. In doing this, the insights and the function of the phenomena discovered, such as ‘innocence’, ‘guilt & shame’, and in the extension to this, the ‘refusal to recover’, are strengthened.

In the exploration of ‘innocence’, in the context of SE-AN sufferers, I refer to the elaboration of the concept of the property ‘staying childlike’, which belongs to the first theoretical category of ‘suffering, but not in silence’ (Chapter 7), and of the property ‘innocence’, which was elaborated on in Chapter 8. With this, I concluded that both concepts (‘staying childlike’ and ‘innocence’) are not entirely similar, although in the context of the women SE-AN sufferers, the concepts are intertwined with each other. Though ‘staying childlike’ appeared through the women’s constructs, ‘innocence’ refers to the self-experience of the women. In the previous section, I explored the concept of ‘staying childlike’ in the extant literature, and in scrutinising relevant studies, I concluded that there is an apparent lack of existing literature referring to this subject. Nevertheless, an indication relating to innocence and childlike behaviour was found in a few studies and similar behaviour was carefully reviewed in the latest Dutch edition of the *Handbook for Eating Disorders* (Noordenbos & Elburg, 2018). Nevertheless, the literature (Noordenbos & Elburg, 2018) did not directly refer to the concept of innocence and childlike behaviour, though I included this finding in an attempt to gain a deeper understanding of the phenomenon. In the contribution by Noordenbos & Lammers (2018), the writers referred to an earlier psychological insight from Bruch (1980). Bruch argued that the development of AN was the result of defective identity development. In this view, AN patients gave priority to the expectations of others (Noordenbos & Lammers, 2018, in Noordenbos & van Elburg, 2018). This view implied the underdevelopment of the self and the autonomy, and is based on a theory by Erikson (the founding father of the 1974 ‘Theory of Psychosocial Development’) and Kohnstamm (2005, in Noordenbos & Lammers, 2018, in Noordenbos & van Elburg, 2018). Their theory came about by the fact that most AN patients developed their illness during puberty or adolescence, and it is precisely this phase, which supports the process of individualisation, where the feelings of control and trust are experienced through the phenomenon of weight loss. With this, it is suggested that the patients experienced a 'voice to stand up for themselves' (Noordenbos & Lammers, 2018, in Noordenbos & van Elburg, 2018). Thus, I concluded that this literature is somewhat important in the contribution to the current empirical findings of this project, in that the women recognised the development of their AN in adolescence and this signalled the persistent presence of innocent behaviour. Furthermore, innocence inferred a 'disguise' in the expression 'having a voice'. This view was also taken in Heenan's[60] (2005) feminist study, which I included on account of the feminist lens[61] that I had chosen. The study also referred to the development of autonomy in childhood, and, as seen from the perspective of eating disorders, a sense of self can be demonstrated by the expression of wishing for, or in the rejection of, specific food. Heenan (2005) stated that food became a transitional object, that could be available for other emotional projections. In addition, this apparently innocent behaviour is considered as perfectly normal behaviour in infants, but is not acceptable in adults. With regards to the current findings in this study, some of Amy's constructs referred to innocence (L64-65). Furthermore, the non-acceptance that Amy clearly experienced from her family, as described in her excerpts (L73-75), exposed this innocence. Although the women SE-AN sufferers were unable to reflect objectively with respect to themselves, they were able to notice this specific behaviour in others, therefore creating a level of ambiguity within this phenomenon. In conclusion, although I consider the literature findings as valuable, the phenomenon itself as a characteristic of SE-AN lacks an in-depth description in existing literature, since the women with SE-AN are convinced that the *innocence experience* contributes to their SE-AN status and thus, innocence contributes to the experience of a diminished quality of life. In this way, substantial support of the need for a deeper understanding of SE-AN patients has been gained.

---

[60] Colleen Heenan, an English psychodynamic psychotherapist, an expert in eating disorders, who strongly supports the feministic approach within psycho-analytical theory, and was convinced of the strong promotion of masculinist influences within this theory. (https://www.psychotherapy.org.uk/therapist/colleen-heenan/),

[61] Section 3.6: Feministic paradigm
Section 4.3: Through the lens of feminism
Section 2.2.4: The quality of life as seen in the context of a feministic perspective

In the elaboration of the second property, 'Guilt & shame versus recovery & success' was revealed, and turned out to be the second key finding of the theoretical category. As also observed in the interviews with the women, shame and guilt are often concealed in metaphors and coping behaviours (Goss & Allan, 2009). Furthermore, shame and guilt confront the patients with their fear of weight gain (Troop & Redshaw, 2012), which is in accordance with the key finding of this project, and illustrated in Figure 8.5: The model of the weight continuum. Thus, in the analysis chapter, I stated that guilt & shame are strongly related to weight gain, and underlying 'hidden' behaviours are also associated with shame. In the literature, several studies referred to the emotions experienced and regarding the feminist perspective. Thus, I decided to include Heenan's (2005) study, whereby she investigated the psychological explanation of the original emotions referring to shame & guilt. Heenan (2005) referred to a range of emotions that were experienced, such as shame, comfort and other forbidden aspects of the 'self', as 'the false boundaries', and defined them as 'psychological splitting' (Heenan, 2005: p 9). With this, Heenan stated that this process is responsible for the construct of a 'false boundary' between bodily experiences and emotions, or even between several parts of the body itself (Heenan, 2005). This psychological interpretation provides a deeper understanding of the complex issues referring to the experience of shame and guilt in the women participants. In compulsive eating, which is also seen in the behaviour of the interviewed women, according to Sandy's excerpts (L133; 195), shame is strongly indicated when women lost control over their eating behaviour. Compulsive eating signifies weakness, for example, which can be provoked by self-imposed goals (Sandy: L122-125; Heenan, 2005). Furthermore, I decided to include a literature review which was conducted by Goss & Allan (2009), which I considered as a powerful research tool with regards to the subject in the context of eating disorders. The study is completely dedicated to the phenomenon of shame, despite the fact that the chronic AN condition is not mentioned as such, and is different than the previous findings by Heenan (2005). Goss & Allan (2009) framed 'shame' as the opposite of 'pride', regarding the onset and the maintenance of eating disorders. The study findings stated that shame is associated with social rejection (Goss & Allan, 2009). Next, 'internal' and 'external' shame is proposed, in terms of ‘what do they think about me’ and ‘how I think about myself’, as described by Gilbert (1998, in Goss & Allan, 2009). The last thought, ‘how I think about myself’, often led to an intensely negative self-reflexion, even to the extent of self-hate (Gilbert, 2002, in Goss & Allan, 2009). Furthermore, in order to cope with feelings of shame, several forms of avoidance behaviour is observed. This behaviour is not only related to skipping meals, but also in the avoidance of mirrors, or even the moments when patients may notice their bodies, and compensate by wearing baggy clothes. Patients attempted to dodge the confrontation with their selves and in the execution of this, they avoid sexual relationships (Goss & Allan, 2009). Subsequently, Goss & Allan (2009) explored the relationship between the aversive childhood and the occurrence of shame in eating disorders. The authors concluded that some studies implied that the growth of shame in eating disorder patients is linked to bullying, specific parenting rules and sexual trauma (Andrews, 1997, in Goss & Allan, 2009). Another study by Waller et al. (2001, in Goss & Allan, 2009), suggested that shame worked as a mediator in the relationship between sexual abuse and Bulimia Nervosa, despite the fact that this particular study made use of only a small sample size and the focus of the study was on Bulimia. In conclusion, I considered the outcomes as valuable, regarding the personal approach in this project, apart from the fact that the appearance of an eating disorder is often unpredictable (Fairburn, 2008).

Then, in the search for an appropriate explanation with regards to the opposite of the earlier elaborated perspective of ‘recovery & success’, I decided not to explore the broad field of eating disorder literature since the chronicity of the AN is often ignored by the exclusion of people with SE-AN from research in this field (Noordenbos et al., 2000). As a result of this sub conclusion, I decided to explore ‘reciprocity’ in the relevant literature. And, according to this subject, Goss & Allan (2009) described reciprocity in the context of ‘the care for others’. By this, they were referring to the affiliation patients experienced within their peer groups. In their peer groups, patients no longer felt isolated or ‘weird’. Moreover, as Goss & Allan (2009) stated, this is a key finding in the motivational factors used to engage the patients in a possible recovery process. According to this assumption, individuals in the group formulated ‘help questions', which may act as a call for a more validated social role. Thus, rather than the 'patient needs help, the patients can help other patients'. Turning back, therefore, to the current findings of this project, and although such reciprocity was not mentioned directly by the women, it is plausible that 'reciprocity' does have a key role in recovery, although unfortunately, this is also the case in the perspective of the persisting illness. Thus, reciprocity, as discussed in this current section, appears as an important factor at the threshold of recovery, and contributes to the diminishing quality of life in the SE-AN sufferers.

Conversely, in the exploration of 'reciprocity', the benefits of the engagement of the 'assistance dog' also emerged from the data. Grey literature sources[62] (Wessels, 1997) brought me to one relevant descriptive study which was performed in the field of social work, and conducted in the Netherlands by Janssen et al. (2017). The study highlights the therapeutic possibilities of assistance dogs in the treatment of eating disorders. Although this research is of limited empirical value in terms of the academic level of the research (Bachelor degree level, in social care), combining the methods they used, for example, the researchers considered the meaning of the professionals as being prejudiced and they assumed that this would negatively influence the results of their research, certain influences can be considered as ideological bias and is opposed to the philosophical stances of GT (Charmaz, 2006; Charmaz, 2008; Glaser, 2007; Glaser & Strauss, 1967). Nevertheless, this is the only study of its kind which refers to the use of assistance dogs in the area of eating disorder treatment. Thus, this finding is, therefore, both unique, and it also highlights an unexpected facet which appeared in my study as an indirect consequence of the interview process. I consider this finding as indirect, since the very presence of a real assistance dog, who was in the company of a participant during the interview, appeared as a conspicuous discovery, as well as that which emerged through the spoken word of the interviews. With reference to Glaser's *"All is data"* (2007: p 2), it is important to include this discovery (Charmaz, 2006). Janssen et al. (2017) concluded that three key

---

[62] https://dutchassistancedogs.nl/wp-content/uploads/2017/11/Praktijkgericht-Onderzoek-MissionPuppy-geanonimiseerde-versie-1.pdf

points emerged, referring to the field of recovery. These key points are as follows: 1) Recovery of physical functions; 2) Recovery of psychological functions; and 3) A fulfilment in social roles and expectations. Moreover, the findings claim that there is less dependency on the patient's social network, as well as a decline in the number of critical moments related to, or provoked by, anxiety or panicking (Janssen et al., 2017). An interesting finding is the idea of forming a 'team' with the assistance dog. The study claims a positive effect on the assertiveness of the assistance dog's owner. In turn, this stimulates the social roles, such as being the 'employee', the 'consumer' or the 'friend'.

In conclusion, the extant literature findings were highly supportive in the defence and the placement of fresh data, as found in the analysis of the theoretical category, 'one step forward, one step backwards'. Although innovative data is not revealed during the analysis of the category, except for the findings which refer to the assistance dog, additional literature findings supported the strengthening of the current findings, which constitutes an increase in the current knowledge with regards to SE-AN patients. Thus, the literature as reviewed in this section appeared to support the findings of the current research, and therefore, this strengthened my position as a researcher. Hence, the findings which emerged are a lasting characteristic with regards to the diminishing quality of life in people who suffer with SE-AN. The SE-AN sufferers maintain the feelings of shame and guilt, but conversely, they also benefit from the reciprocity that people with SE-AN receive from their AN. In addition, it was also revealed about the benefits which could be gained from having an assistance dog, that could improve their quality of life and provide companionship, which is a reciprocal situation. This is in direct contrast to the relationship that some women SE-AN sufferers describe when they approach their 'anorexia' as their friend (Goss & Allan, 2009), or as a protector (Williams et al., 2015), although such an approach can be detrimental to them and can cause on-going damage. This issue warrants serious attention from professionals in terms of therapeutic alignment.

11.4 Discussing the core category: 'Connective tissue'

In Chapter 9, the theoretical category ‘connective tissue’ was explored, and ‘communication’ through the AN condition emerged in the context of the human contacts of the women. The three properties revealed the following key findings: ‘Maintaining the SE-AN condition’, Contacts and connections with others’ and, finally, ‘AN is a conductor’. Through the analysis, an insight was gained to the effect that communication difficulties are caused by the obedience to the AN, and the wish to break free of it. Furthermore, the analysis of the properties identified a complex two-dimensional relationship. On one side, there are the other people in the social world, such as relatives, healthcare workers, but on the other side, there is the interfering relationship with the AN itself, which appeared to be closely related to the personification of the AN that the women experienced. In addition, there is the reality in which SE-AN sufferers live, that creates a fragile balance in maintaining the values in relationships with both other people and with the AN itself.

The first property to be revealed was ‘maintaining the SE-AN condition’, whereby there was a subtle interaction to stay in contact with others *through* the SE-AN condition and, in this way, an AN reality was created. The second property explored the ‘contacts and connections with others’. The findings indicated that the AN condition provided the women SE-AN sufferers from their contacts. Though, the opposite was also noticed, an increase of distance amongst people because of the SE-AN condition appeared. Typically, the second property underpinned the phenomenon ‘to be noticed’, which can be counterproductive because of the influences of the ED practices on the patient’s behaviour and their thoughts. The third property explored the data in terms of the ‘AN is a conductor’. This identified the interfering power of the persistent AN status, and how the women attempted to create a distance from it. Nevertheless, this property discloses the common opposites, whereby the women experienced a certain force from the AN condition, the women experience an intense suffering from the condition, although they demonstrated dependence and are not able to resist it. The following figure (Figure 11.4) suggests the intervening of the key findings, which together form the core category and are pivotal for a diminishing quality of life:

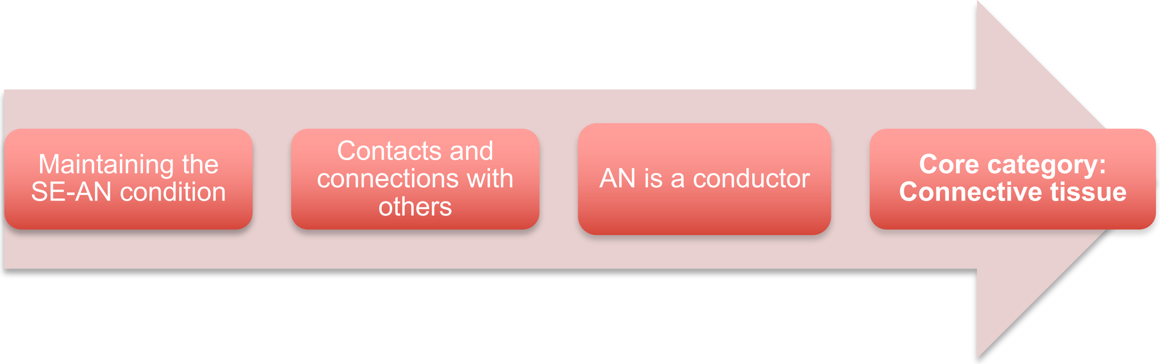


Figure 11.4: Development of the core findings of the third theoretical category

The arrow suggests the development process of the core category, which is built on the key findings in the area of communication. In the process of gaining an in-depth understanding, guided by the key findings, each key finding was carefully explored in the extant literature. As a result, the current findings emerged, and, the existing data is strengthened through the addition of more empirical data.

In order to make the key findings more prominent, I included them in Box 3 below:

Key findings:

Maintaining the SE-AN condition

Contacts and connections with others

AN is a conductor

Box 3: Key findings of ‘Connective tissue’

By the addition of the data that emerged, which referred to the first key finding, ‘Maintaining the SE-AN condition’, a literature search was then conducted in order to gain a greater insight

(Charmaz, 2006; Glaser & Strauss, 1969; Glaser, 1978). The key finding highlighted how the people with SE-AN relate to today's reality in terms of their daily functioning. To stay close to the constructivist approach (Charmaz, 2006), a relevant literature search was conducted in respect of 'reality'. Although the more general, but adequate findings are linked to 'reality experiences' and refer to the interference of the AN condition which indicate the core diagnostic characteristics of the disease (such as 'disturbed body image' and 'intense fear of weight gain'), a more accurate description of the phenomenon of 'reality' seems to be lacking. Furthermore, certain characteristics can also be applied to the acute AN patients, as it appeared that these phenomena also influence the experienced reality of the patients (Espeset et al., 2011; Touyz et al., 2013; Tchanturia, 2014). In addition, with regards to current treatment programmes which address a decrease of certain characteristics, more positive treatment results were reported in younger patients with an acute form of AN (Agras et al., 2014; Lock, 2015). This is due to the fact that short-term treatments seem to have a minimal effect on the persistent thoughts relating to weight, food and body shape, which makes the phenomenon of SE-AN even more idiosyncratic (Touyz et al., 2013).

Next, the mixed method study, which was conducted by Arkell & Robinson (2008), created a twofold perspective: the positive and the negative avoidance perspectives relating to the SE-AN position, which is linked to the experienced reality of SE-AN sufferers. Initially, Arkell & Robinson (2008) referred to the term 'interpersonal avoidance', due to its positive effects. The Arkell & Robinson study (2008) claimed that 'trust' and 'rely on the AN' were significant in that the SE-AN participants experienced AN as an excuse to keep others at a distance. Regarding the negative effects of the eating disorder, the study indicated 'social isolation' as a result of obedience to the eating disorder, which is also linked to their 'reality'. The writers concluded with the following observations: 'not belonging to the real world' and 'the real world becomes more and more alien and difficult to remain in*'* (Arkell & Robinson, 2008).

Regarding the constructs of this study, the literature findings, as described above, intervene and strengthen the key finding 'maintaining the SE-AN condition' that was discovered, and thus, the women SE-AN sufferers emphasise the maintenance of their own reality in their societal worlds. Overall, the loss of reality strengthens the negative impact that SE-AN has on their relatives and their social life. It seems to increase the powerful effects of the illness on the cognitive position, whereby a vicious circle is implied, and effects of this may be responsible for a diminishing quality of life. And, this is precisely why SE-AN sufferers should receive professional attention in the area of 'reality'. This attention needs to be specifically designed in order to support people with SE-AN in increasing their quality of life. Thus, the key finding 'maintaining the SE-AN condition', contributes to a deeper empirical insight with reference to the experienced reality of SE-AN sufferers, and thus, more attention is necessary in order to improve the quality of life.

The second key finding 'contacts and connections with others' appeared during the data analysis. Because of the feminist perspective which was used in the study, relevant literature was found in the work of Heenan (1996). I considered Heenan's work as appropriate regarding the feminist view due to the fact that the phenomenon of 'communication and contact experiences' *through* the eating disorder is addressed in her work (Heenan, 1996). However, Heenan (1996) classified the ED as a label, rather than as a medical condition. This issue demands attention because of the severity of the diagnosis, which all the women participants agreed upon, and which is underpinned by the following excerpt from Sarah (L: 83):

> *"It's really a disorder, because I think if it was an eating problem, I could have so much more control of it. And when it becomes stronger, I lose control totally. I really can't influence my behaviour. Others might say in their despair, please eat! And I think, "I want to, and I should do that, but I really, really can't. I feel that I have no choice at all. For me, it's a disease."*

Then, conversely, suffering from an ED can be responsible for the development of an identity, which also suggests societal exclusion (Heenan, 1996). In communication, Heenan (1996) recognised the phenomenon of 'downsizing' the ED by the women themselves, as a method of ignoring their personal distress (Burstow, 1992, in Heenan, 1996). In addition, other research has indicated that the AN condition helped AN patients to communicate, and with this, other people realised that people with SE-AN experienced certain difficulties in the area of communication (Nordbø et al., 2006). The study findings illustrated communication 'through the body', whereby other people were able to observe the problems the AN participants experienced (Nordbø et al., 2006). Such findings were similar to a study by Fox & Diab (2015). In the context of loneliness and disconnection from the social world, the AN gained attention, and by the increase of the illness, others provided them with more care and attention. This also suggests that the adoption of the AN identity makes recovery impossible, as maintaining the AN condition has become a type of sanctuary (Fox & Diab, 2015).

In the current Dutch guidelines[63] [64], a disruption in the communication of people with ED is indicated, which may lead to challenging behaviour, such as lying and manipulative behaviour (Arkell & Robinson, 2008), and it is assumed that certain behaviour influences the contacts between the patient and close relatives and friends. Often, certain behaviours arose from fear, relating to food and weight gain, and these phenomena can be considered as some of the core symptoms in eating disorders. Nevertheless, this could have a negative impact on communication within the social world. Typically, I considered these literature findings as an empirical underpinning of the property that was revealed, which reinforces the theoretical category 'connective tissue'.

The third key finding concerns the property 'AN is a conductor'. Some competent studies described the phenomenon of the 'anorexic voice' (Abbate-Daga et al., 2013; Tierney & Fox, 2010). In this project, the data referring to the subject revealed a more subtle finding investigating 'AN is a conductor' and which uncovered communicational disruptions. The communication difficulties that emerged were caused by the obedience to the AN versus the wish to break free from it. With this, I decided to search for more appropriate studies referring

---

[63] https://www.nursing.nl/patient-met-anorexia-het-ziekenhuis-9-tips-voor-een-goede-bejegening/

[64] https://www.ggzstandaarden.nl/zorgstandaarden/eetstoornissen

to the topic of the quality of life in people with SE-AN, in combination with the key finding that emerged. Less relevant studies demonstrated additional data, which enabled me to compare my findings with existing sources (Charmaz, 2006). Nevertheless, the current findings strengthened knowledge of the SE-AN phenomenon, and made the findings relevant. Two phenomenological research studies by Fox & Diab (2015) and Wright (2013) described the theme of 'battling with anorexia' in their articles. This theme referred to the control experienced by the participants *through* the AN, and at the same time, control was taken away from the SE-AN participants *because* of the AN status. In the study by Wright (2013), she examined 'battling' with the AN condition, as seen through the eyes of the care workers. The care workers noticed the parasitic condition of the AN that controlled the patient. Moreover, a similar process occurred in the phenomenon of connections and relationships. The AN status provided patients with a certain confidence, while conversely, SE-AN patients felt isolated because of the AN status (Fox & Diab, 2015). Furthermore, in the study by Arkell & Robinson (2008), regarding the negative aspects of the SE-AN condition, the authors described the difficulty experienced by the patients in breaking daily routines, such as visiting friends and family, which the SE-AN sufferers felt was dictated by the ED. As shown in capital letters, the study demonstrated the following sentence: *"THE CELL I HAVE BUILT FOR MYSELF"* (Arkell & Robinson, 2008: p 654). This statement stands for itself, and is highly relevant to the current key finding. As an example, I added an excerpt from Amy, where she referred to the same principle:

> *"He is in the lead. He determines what I do and what not, and of course, I am in his power."*
>
> (Amy: L102)

Generally, although fewer literature findings referred to this topic, additional findings do still underpin the necessity for such findings as were revealed in this study. The key finding, 'AN is a conductor', represents a deeper insight into the experienced quality of life of people with SE-AN, and thus it contributes to the empirical knowledge in the context of communication.

In conclusion, the extant literature findings supported the defence and placement of the fresh data as found in the analysis of the theoretical category, ‘connective tissue’. Although less additional literature data was found during the analysis, additional findings supported the strengthening of the current findings, which constituted an increase in the current knowledge regarding the experienced quality of life in SE-AN sufferers. Overall, the literature findings supported the strengthening of the current findings in this study. Moreover, the literature findings that emerged provided a consistent factor in the diminishing quality of life in SE-AN patients, and thus, the communication strategies of people with SE-AN as developed by their SE-AN condition, deserved serious attention from professionals in terms of therapeutic alignment.

11.5 Discussing the core category: ‘Best friend, best enemy’

In Chapter 10, the theoretical category, ‘best friend, best enemy’, was explored through the emergence of three properties, which led to the three core findings: ‘The personification of AN’, ‘Attributing blame’ and ‘Alignment to therapists’. Together, they revealed new insights into the relationship relating to the acceptance of the SE-AN status versus the perspective of recovery, which suggested a tension between the acceptance of SE-AN and the ‘wish to break free’ of the AN. Initially, the premier key finding, which suggests the ‘personification of the AN’, was discovered and explored. With this, a new insight was gained into the relationship between acceptance of the SE-AN condition and maintaining control over the lived experiences. The second and the third properties revealed the following key findings: ‘blame attribution’ and ‘alignment to therapists’. They illuminated the function of the maintenance of the SE-AN condition, which led to a particular status relating to the QoL in the women SE-AN sufferers. In the current chapter, one cohesive construct is presented by discussing the key findings in comparing them with, placing them in and defending them against, the existing literature.

The key findings of the ‘Best friend, best enemy’ category, which present the SE-AN sufferers’ personal experiences in terms of their AN condition, are reproduced in three key findings. Together, they identify how the SE-AN patients cope with the powerful force of the AN, whilst also staying in contact with their societal world *by means of* their SE-AN condition, which suggests a complex and diminishing quality of life. Thus, certain behaviour is characterised by the continual tension between ‘the obedience of the eating disorder and the wish to break free’, which is embedded in the key findings. As used in the previous sections of this discussion chapter, I used the same arrow illustration (Figure 11.5), which appears below. In doing this, I pursued transparency with regards to my thinking process in the data analysis. The arrow suggests an accumulating process and, together, the key findings of the core category of ‘Best friend, best enemy’ are responsible for a diminishing quality of life.

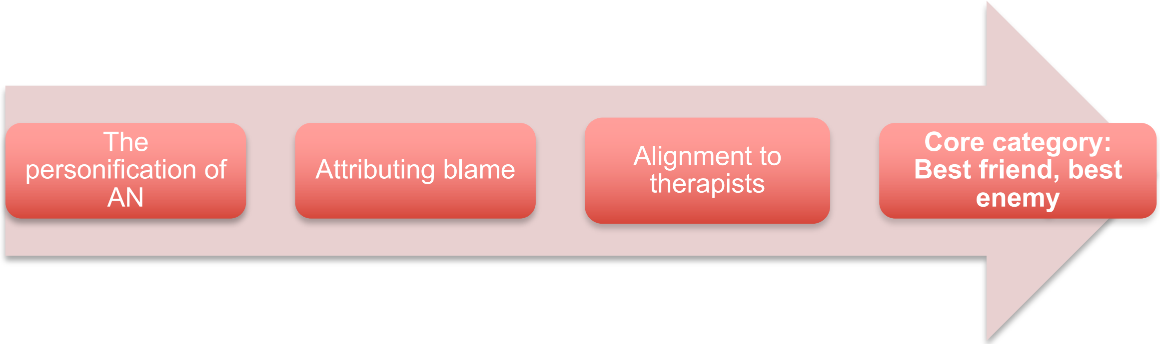


Figure 11.5: Development of the core findings of the second theoretical category

The arrow indicates the development process of the theoretical category, and the key findings lead to a robust category, suggesting the area of acceptance of the SE-AN status, as opposed to the maintenance of the control through the AN condition, as described in a metaphor. In the next section, the key findings will be carefully explored in the extant literature, and with this, the findings will be compared in order to defend, place and compare them with the existing data in the pursuit of strengthening the current findings.

In the attempt to make the key findings even more conspicuous, they are shown in Box 4 below:

Key findings:

The personification of the AN
Attributing blame
Alignment to therapists

Box 4: Key findings of ‘Best friend, best enemy’.

The data processing of this study led to the first key finding of the fourth theoretical category, ‘the personification of AN’. It was then appropriate to compare the findings with the additional data (Charmaz, 2006). The constructivist approach of Williams et al. (2015) was used to examine the extant literature, in respect of the similarities in the study design and subject. In addition, Williams et al. (2015) focused on women’s suffering from a lifetime history of AN, and they noticed that the AN quickly became a part of the individual. In referring to the finding, this gave the person with an anorexic identity the concept of *“the AN is me”* (Williams et al., 2015: p 11). Moreover, the identity was described in terms of the ‘control’ it had over the person (Williams et al., 2015). The ED was considered as having its own voice, and hence, that it dictated the actions it expected the person to carry out (Williams et al., 2015). With this important finding, the relationship in the control and the AN identity is described, and strong similarities were recognised with the findings of the current study. Furthermore, Conti (2018) examined the women’s constructs of recovery from AN over a 10-year period and concluded that people learned to live with the AN condition by controlling it (Conti, 2018). In this study, control is indicated differently, whereby the women experienced control in dealing with the ED to protect them against relapse (Conti, 2018). In this way, reciprocity is implied, which is also an empirically-embedded finding of this study. In addition, loss of control was also found to be an important factor in the maintenance of the ED, and with this, the retaking of control of *life* contributed to the recovery from AN (Newell, 2007). In other words, letting go of the ED control represents recovery. From this, I concluded that the 'personification of AN' is not a new finding, though the extant literature findings contributed to the strengthening of the current findings, whereas this key finding supports the disclosure of the core category 'Best friend, best enemy', which stands for the tension between acceptance of the SE-AN condition and the 'wish to break free' from the disease. Furthermore, this apparent impasse contributes to a diminishing quality of life.

In the search for valid literature findings relating to the key finding 'attributing blame', this approach is strongly related to 'alignment to therapists'. In other words, 'blame attribution' functions as the key in the access and arrangement of professional care. With this in mind, I decided to compare the key themes in several equivalent qualitative study approaches and other appropriate scholarly publications in the search for possible similarities. However, only a few representative studies were uncovered, as there appears to be a lack of expertise in the existing data referring to this specific area. A qualitative analysis by Robinson et al. (2015) revealed the following finding that, in the realm of treatment, the need for a strong therapeutic relationship is important (Robinson et al., 2015). Nevertheless, the findings of an interpretative phenomenological study by Fox & Diab (2015) suggested some complications due to the fact that the staff of SEDUs did not always fully understand the SE-AN sufferers. Patients' interviews referred to the fact that they 'felt let down', and experienced staff members who did 'not have the necessary knowledge according to the SE-AN', and thus, according to the patients, the staff expressed pessimism, which was a problem experienced by the patients (Fox & Diab, 2015). Conversely, Fox & Diab (2015) also described that patients idealised specialist care. Despite this finding, in the case of 'alignment to therapists', Robinson et al. (2015) strongly advocated the need for a professional alliance for the care of people suffering with SE-AN (Robinson et al., 2015), which is in accordance with the views of Strober (2010), Elzakkers & van Delden (2018, in Noordenbos & van Elburg, 2018) and Touyz & Hay (2015). The last writers referred to a heart-breaking statement for the improvement of therapeutic alliance abilities:

"Those living with a chronic illness, especially one as deliberating as SE-AN, are entitled to dream of a better tomorrow and to feel understood not only by the medical profession but by the world at large" (Rego, 2015, in Touyz & Hay, 2015: p 1).

In addition, Touyz & Hay (2015) proposed that a significant amount of research funding went into other areas of health care and, although the authors did not suggest that other areas of health care were unimportant, they strongly advocated the inclusion of funding for vulnerable people such as SE-AN sufferers, and that they were entitled to long-term and decent care. Wright & Hacking (2012) also described the necessity for a therapeutic alliance for Anorexia patients. Patients appreciated the proposed safety and care given by professionals. These and other findings indicated that professional healthcare engagement with SE-AN sufferers in a nurturing environment were more important than targets that were directly linked to physical recovery. In general, despite an apparent lack of a broad range of literature in this specific area, the findings, as described above, do contribute to the importance of the need for therapeutic alignment, and thus, access to a professional alliance for SE-AN patients. Furthermore, the lack of a therapeutic alliance appears to affect the quality of life in people with SE-AN.

11.6 Summary

In this chapter, I have presented the twelve key aspects which have been revealed in the analysis chapters, Chapters 7, 8, 9 and 10, according to the constructivist techniques of Charmaz (2006) by placing, comparing and defending them against the extant literature, With this, I have contributed to an increased understanding of the quality of life as experienced by people suffering from the SE-AN condition. The literature findings, merged with the current study's findings, have also contributed to a deeper understanding of the social processes which were observed in the current study project. The constructs and thoughts of the SE-AN sufferers have been revealed and compared with the existing literature on the topic and, if possible, they have also been compared with other available equivalent study designs. In this chapter, each theoretical category has revealed several key themes, which I highlighted by using illustrations, such as boxes and process arrows. In doing so, I created transparency into my thinking strategy, which benefitted the reliability of the findings. In the following chapter, I present the implications for the application of the findings in practice.

Chapter 12 Conclusion

12.1 Introduction

In this chapter, I focus on the outcomes of the project, elucidating the theoretical worth of the findings and their impact in describing the four key messages with regards to the aims of this study[65]. Charmaz (2006) stated that findings are considered as part of the grounded theory, being the logical result of the GT process. It is the case, therefore, that the key messages are integrated into this conclusion chapter. Regarding the constructivist approach, the findings are built on the subjective constructs of the women SE-AN sufferers, and therefore, the findings are extremely valuable in the context of a personalized approach to healthcare, such as is suggested in the treatment of the SE-AN condition (Charmaz, 2006). By revisiting the aims of this study, the four key findings are demonstrated as being highly supportive in offering an appropriate treatment for the SE-AN condition. In addition, in examining the proposed aims, an in-depth understanding of the phenomenon should be gained, in terms of 'the experiences

---

[65] Chapter 2, Section 2.6.1: Aim and objectives.

of life', as influenced by the symptoms of severe and enduring Anorexia Nervosa. With regards to the objectives of this study, they seek to provide new insights into the lived lives of people with the severe and enduring form of the condition. With the new insights gained, therapists can contribute to the empowerment of SE-AN sufferers, and can provide a deeper understanding of the illness, which is especially relevant in the empowerment of, not only people with SE-AN, but also their relatives and their friends. With this, an improvement in the quality of life of the person with SE-AN may be reached.

Chapters 7, 8, 9 and 10 identified the twelve key findings, which are related to each other by the four key concepts of 'suffering, but not in silence', 'one step forward, one step backwards', 'connective tissue', and finally, 'best friend, best enemy'. Together, they account for the formed behaviours in the patients' interactions with their relatives and friends, the healthcare professionals and their other social contacts. The emergent key findings validated the interpretation of the influences on their lived quality of life. In addition, the study provided an improved insight with regards to the SE-AN sufferers' engagement through the delineation of the key processes that people with SE-AN draw on in understanding their relatives, their friends, the healthcare professionals and in other social interactions. Moreover, the study provided insights into how people with SE-AN formed their behaviour in response to their social environment, which subsequently informs SE-AN sufferers how to behave regarding the outcomes of the quality of life.

This study contributes to the existing body of knowledge, which I revealed through the operationalisation of proposing the four key messages. Together, a theory is formalised in the approach and the support of people suffering with SE-AN, regarding the improvement of their quality of life. In the work of Charmaz (2006), she defined the concept of a constructivist theory by placing the theory against the positivist stance. Charmaz (2006) uses the following definitions: *"A positivist theory seeks causes, favours and deterministic explanations, and emphasizes generality and universality"* (Charmaz, 2006: p 126).

This interpretation clearly challenged the interpretative definition, which applies in this project and is as follows:

> *Interpretative theory calls for the imaginative understanding of the studied phenomenon. This type of theory assumes emergent, multiple realities; indeterminacy; facts and values as linked; truth as provisional; and social life as processual.*
>
> (Charmaz, 2006: p 126).

In this project, I have met the criteria as referred to above, and furthermore, I critically analysed and interpreted the several quantitative data sources which I have used, in an attempt to make this thesis, and thus, its findings more robust and valuable for daily practice.

Hence, in this chapter, I clarify the four key messages responding to the four core theoretical categories which emerged from the data analysis. Firstly, I start with the principal key message of ‘suffering, but not in silence’, followed by the presentation of the key messages relating to the second core category, ‘one step forward, one step backwards’. Next, the key messages of the third and the fourth categories will be presented for the theoretical categories ‘connective tissue’ and ‘best friend, best enemy’ respectively. Finally, I present the study limitations and strengths, followed by a general thesis conclusion.

12.2 Key Message One: Recognising suffering as a continual additional effect in the approach of SE-AN sufferers

Initially, in this section, I begin with the elaboration of the first key message in answer to the most important finding, that is, the continual suffering, which is recognized as multiple suffering. I considered the theoretical category as pivotal because of the severe effects that the continual anorexic status provokes. However, in gaining a deeper understanding of this key message, an explanation of this important view is significant in terms of evidence-based practice in public healthcare. Thus, the following stance can be applied to all four key messages. This stance regarding healthcare policy becomes increasingly important in working with current and valid guidelines in healthcare contexts, in reference to *The Dutch Guidelines for Eating Disorders* (Zorgstandaard Eetstoornissen, 2017), *The Royal Australian and New Zealand Practice Guidelines* (Hay et al., 2014) and *The National Institute for Health and Care Excellence* (NICE, 2017). Certain guidelines recommend that healthcare professionals should have specialist knowledge and skills in the understanding of, and the engagement with, eating disorder patients, regarding the promotion of healthy attitudes, as seen in the light of a curative pathway, which I would agree with. Nevertheless, the current guidelines do not suggest a prominent treatment approach regarding the SE-AN condition, although some attention is given to this group. In light of this, I refer to Hay et al. (2014) and the Dutch guidelines (2017), and I consider this an improvement over previous versions of these guidelines. Despite progress being made in the guidelines, challenges still remain. The guidelines do suggest a therapeutic alliance, based on shared decision-making, however, patient and healthcare profession perspectives are not always aligned. And, with reference to Wright (2010; 2013) and Strober (2010), since a therapeutic relationship is crucial for a successful treatment, a shared understanding of the aims and expectations should exist between the healthcare professional and the patient. With this in mind, a better co-ordination in the prevention of setbacks and misperception is promoted, and preferably is put in place prior to the care process. Logically, this requires excellent communication skills, which are considered as highly pertinent in the improvement and conservation of the therapeutic relationship (Wright, 2013).

Regarding the current findings in the disclosure of the data relating to ‘suffering’, from this study’s point of view, the SE-AN phenomenon warrants a greater understanding of the specialised knowledge of professionals, given the fact that the themes related to suffering are pivotal. With this in mind, it is reasonable to validate the suffering that is experienced by the individuals, by exploring the possible dimensions of the suffering experienced. In this way, the professional is better able to find a connection with the individual, to provide personalized care and to centralize any requests for care. Likewise, professionals should be aware of not being too naïve in the care process, which means not appearing too enthusiastic in the progressively changing phenomenon of suffering, given the fact that suffering is a functional method of communication. This is especially the case in the suffering identified in how SE-AN patients interact, and how they form behaviour in order to stay involved in their social world through their SE-AN condition. In considering this finding, openness is required in the expectations of the professional and of the SE-AN patient, as well as any other people involved. Moreover, this requires certain core behaviours from the healthcare professional, such as tact, honesty, flexibility and a deeper understanding of the SE-AN phenomenon in respect of all involved parties, as well as offering and providing access to either palliative or curative treatment in terms of physically comorbidity. Thus, in the treatment of SE-AN, appropriate preparation is essential regarding the background of the specific SE-AN condition, along with supplemental supervision with other healthcare workers regarding the treatment of people with SE-AN.

Ideally, professionals should be prepared to have discussions about mortality rates and the risks posed to life by the continual status of the SE-AN condition (Harris & Barraclough, 1998; Roux et al., 2013; Keshaviah et al., 2014; Brown & Mehler, 2015; Steinhausen, 2002; Harbottle et al., 2008). Some of the women participants revealed their awareness of the risk they carried and inferred that they would value more open discussions about this topic (Mariah: L271; Fiona: L65; Sandy: L193; Amy: L159-161). Nevertheless, they often avoid such discussions, as they are afraid that they will be judged as behaving irresponsibly because of their illness, and thus, because of their situation (see also Memo 11). A similar recommendation could be to provide the exploration of an 'end of life' pathway, for those severely physically compromised and damaged by their SE-AN condition and who are resistant to treatment, and hence, a premature death might be inevitable.

12.3 Key Message Two: Validating the cyclical process of 'adaptation versus rejection' of the Anorexia Nervosa status

In the presentation of the construction of 'one step forward, one step backwards', a personal and complex structure of the women SE-AN sufferers was identified. A constant tension is suggested, regarding adaptation versus rejection of the AN, which emerged through the lens of the developed weight gain and weight loss continuum. It is likely that people with SE-AN are aware of the scale of risks associated with low weight, and how they might benefit from increasing their weight by considering treatment, and they are also aware of how several other complaints contribute to their diminishing quality of life. Clearly, the 'sub-diagnosis' of SE-AN requires the alliance of at least one, or preferably more, appropriate treatments, regarding the diagnostic criteria[66] (Bamford & Mountford, 2012; Strober et al., 1997; Touyz et al., 2013; Robinson, 2015). As a result, SE-AN should be acknowledged by psycho-education in general. While the analysis of this study revealed the cyclic process, in which a delicate balance appeared between the properties 'shame and guilt' and 'recovery and success', a delicate balance was also observed between 'shame' and 'guilt', and consequently the fear of weight gain was noted, which is also responsible for the preservation of shame and guilt. Typically therefore, this process prevents recovery (and a lack of success), and usually contributes to the maintenance of a low weight.

In this section, I propose several suggestions regarding the phenomenon, whilst also being aware of the possible risks that the proposed management may create, which is in accordance with Strober's (2010) view and also that of Touyz (2013). In their studies, they strongly advocated the following stance, and with this, I decided to repeat the section as written in Chapter 2, because of the impact it might have. In Section 2.4[67], I wrote:

> *The health care professionals identify the need for non-specific medical palliative care on patients with SE-AN (Strober, 2010; Touyz et al., 2013). According to Strober (2010), Williams (2010) and Touyz et al., (2013) full recovery from every manifestation of SE-AN should not be the primary goal in treatment for individuals with the SE-AN condition. The focus should be on the improvement of the quality of life and the avoidance of failure experiences in treatment, which might further discourage patients (Touyz & Hay, 2015).*

---

[66] Chapter 2, Section 2.1.5: Severe and Enduring Anorexia Nervosa.

[67] Chapter 2, Section 2.4: Treatment of Severe and Enduring Anorexia Nervosa within the SEDU.

Thus, as seen from my perspective in specialised care, an appropriate professional treatment, with respect for the individual's request for personalised help, as seen from the patients' perspectives, must be offered, even if the patient makes a palliative care request. This perspective requires, at least, a twofold approach:

Firstly, an adjustment to the therapeutic 'landscape' is required, regarding the lack of specialised knowledge of the SE-AN condition. This can be realised by offering nationwide training in the form of the dissemination of knowledge by the implementation of e-learning modules, along with further attention to the topic through conferences. Secondly, active co-operation needs to be sought with the Flexible Assertive Community Treatment (F-ACT) teams of the Dutch mental health institutions (https://www.f-actnederland.nl/). F-ACT professionals should be offered specialist training by the eating disorder professionals, in the treatment and support of SE-AN sufferers. But also thirdly, in addition to the first two recommendations, and with regards to Strober (2004a, in Grilo & Mitchell, 2010), psycho-education should be offered, with reference to the developmental model of chronicity in terms of the improvement in the quality of life experiences (Strober, 2004a). This encourages patients to establish daily routines regarding their social contacts and their hobbies.

Furthermore, professionals should plan regular meetings with families and other important people in the lives of the patients, regarding education into the chronicity of the condition, and should support them in accepting SE-AN in their loved ones. However, a review which includes several family treatment approaches in a total of 25 studies (Fisher et al., 2018) suggests there is little evidence to support the effectiveness of family therapy and, although the authors argued regarding the low quality of the studies included (Fisher et al., 2018), Strober (2004a, in Grilo & Mitchell, 2010) still advocates the involvement of family, but without the use of too rigid an approach. Family sessions are important in helping the patient accept that there will be times when it might be too painful for the loved ones to be with the patient. Finally, through the study, I became aware that the companionship of, and taking care of, an assistance dog appeared to be a significant comfort for some of the women. One possibility is to include contact with an assistance dog via collaboration with a professional assistance dog worker, whereby these professionals take responsibility for the dog. Another possibility is to suggest the help from an assistance dog. Clearly, this option does not suit everybody, nor is it always possible. Nevertheless, this does not make the finding any less valuable.

With this stance, SE-AN patients might benefit from supportive help in their own environment, which may contribute to an improvement in their quality of life, in that this may negate the need for in-patient treatment. With the type of treatment suggested, SE-AN sufferers will be offered tailor-made support, and they will be treated more respectfully, even if the approach is about dealing with a possible life-threatening situation. One advantage of the proposed form of treatment is the possibility of a reduction in healthcare costs, as a result of a reduced need for in-patient treatment.

12.4 Key Message Three: Recognising the impact of, and respecting communication *through* the SE-AN condition

During the analysis, communication *through* the AN condition emerged, in respect of the women SE-AN sufferers contact with other people. The three key findings suggest multiple communication structures, which may be responsible for the communication difficulties that emerged from the study, and are rooted in two opposing characteristics. Firstly, there is the obedience to the AN, and secondly, the opposite view of wishing to break free from the AN condition. The analysis then identified a complex two-dimensional relationship in the context of communication, which includes patients' relatives, other social contacts, as well as communication with healthcare workers, set against the interfering relationship with the AN itself. Furthermore, it is suggested that the created reality, which is constructed by the SE-AN sufferers, is responsible for the fragile balance between maintaining values in relationships with both people and with the AN. A key finding of the core category suggests that the maintaining of the SE-AN condition is pivotal, wherein is the key finding of the lived and created reality of people suffering from SE-AN.

The second key finding, regarding social contacts and connections, underpinned the phenomenon of ‘to be noticed’, which can be counterproductive in terms of the influences the condition can have on the women’s behaviour and thoughts. It reveals the interfering force of the continual AN condition, versus the attempt of the women SE-AN sufferers to create a distance from it.

In the improvement of the quality of life in SE-AN sufferers, it is worthwhile to acknowledge the effects of a possibly disturbed perception that patients may experience. Their loss of reality is strengthened by the negative impact SE-AN has on both their families and their social lives, and, in turn, this may increase their burden by experiencing the powerful effects the illness has on the patients’ thought processes, and thus, a vicious circle is implied. However, certain effects do need the attention of professionals and other people who are involved. As stated earlier, customized psycho-education is needed for all involved people, including the healthcare professionals who are involved, such as nurses, psychologists, psychiatrists, GPs, etc.. This meets the individual’s criteria of being specific, and it respects the shared decision-making approach. In this way, the SE-AN sufferer takes control regarding the choice of people who will be involved in the treatment.

12.5 Key Message Four: An adjusted paradigm

The analysis revealed the theoretical category ‘best friend, best enemy’, whereby the three key findings, ‘The personification of AN’, ‘Attributing blame’ and ‘Alignment to therapists’, emerged. With this, a deeper understanding was gained in terms of the acceptance of the SE-AN condition, and conversely, in the maintenance of control, as experienced by SE-AN sufferers *through* the AN condition. Generally, the current perception of the professionals involved might actually contribute to a diminishing quality of life, in that people with the SE-AN condition do not always have unconditional access to the SEDUs or to other trained professionals. Nevertheless, by revealing such findings, this explicitly claims unconditional access to healthcare professionals for SE-AN sufferers, without imposing impossible control over the SE-AN condition, by referring to the request for an adjusted paradigm:

> *Full recovery from every manifestation of SE-AN should not be the primary goal in treatment for individuals with the SE-AN condition. The focus should be on the improvement of the quality of life and the avoidance of failure experiences in treatment, which might further discourage patients (Touyz & Hay, 2015).*

The statement as above justifies and emphasises the severity of the condition in terms of how the disease manifests itself. With regards to this, I would recommend that all professionals, when interacting with patients with SE-AN, take into account the following points to improve of the quality of life within SE-AN sufferers which are described in the next section 12.5.1: Recommendations.

12.5.1 Recommendations

In this study I have attempted to provide a clear presentation of the lived experiences of the SE-AN patients, which were linked to their quality of life. To make the findings useful in daily practice, thus, with regards to the usefulness of this constructivist GT, I stated the following recommendations:

- be inclusive with SE-AN patients; do not reject them, be respectful in what can sometimes be a deplorable situation;
- make a referral if necessary;
- where comorbidity has occurred, search for appropriate recommended collaboration with other trained professionals, and;
- be up-to-date with current knowledge relating to the SE-AN condition;
- divide the care for SE-AN people among other practitioners;
- avoid, if possible, hospitalisation in general care;
- be respectful to and collaborate with the SE-AN sufferers and the important people in their lives;
- consider the possibility of an assistance dog, and if considered appropriate, make a suitable approach to the SEDU, due to the possible presence of assistance dogs;
- consider professional training in ‘end of life’-type discussions;
- put training in place for the professionals, other important contacts and any other uninformed people

In conclusion, regarding the four key messages, which I related to the core categories, and as elaborated on in the previous analysis chapters (Chapters 7, 8, 9 and 10) and which I carefully scrutinized on their value by discussing them through literature research (Chapter 11), I consider the findings to be powerful enough to improve the approach, the care and treatment of SE-AN people.

Each section was supported by several key messages, equipped with some practical guidelines for professionals and other involved people which have a substantial impact on the perceived diminishing quality of life of people with the SE-AN condition.

12.6 Study strengths and limitations

Identifying the study’s strengths and limitations is of great relevance to this project, as it reinforces the empirical importance which the study represents. This is especially the case, as the findings will be placed in an empirical context. They provide insight into potential errors which may be caused by the use of other methods of data gathering, analysis and interpretation. I start this section by highlighting the strengths and benefits of the project. With this, I explicitly refer to the comparative process, starting with a struggle with seemingly similar data, but in ‘each round’ new, additional, and generally important findings emerged, although, at the start, I lacked the skills to interpret the findings adequately. Remembering the statements which were made by my supervisors (Professor Wright and Dr Duckworth), ‘*The data will appear’*, it was extremely helpful in improving my personal research skills, especially by organising the 3-day meeting, where the complete supervisory team carefully scrutinised the data. Once this most important start was made, I experienced a significant growth in my research skills and in the understanding of the data, and thus, in the development of the constructivist approach. The completion of this process benefits the rigour, the openness and the flexibility of the study, which is particularly important in conducting a constructivist grounded theory approach to research. Then, with regards to the feminist perspective as used in this study, the emerged findings can be considered as unique and emerged recommendations ought to be proposed as tailor made. Thus, the findings also to be of importance and useful in the approach of male SE-AN sufferers, bearing in mind that the tuning of appropriate help in a shared decision-making process is always necessary.

It is also important to identify the study's limitations in terms of encouraging further debate into the topic. However, not every project acknowledges their study's limitations, resulting in the generalising of data due to a lack of transparency, which might influence the external validity (Poelman, 2015). Regarding the constructivist approach, as used in this project, the demonstration of the reflexivity is essential in terms of the topic of this study, the data collection and the application of the practical findings. Furthermore, this study recognises the following limitations:

Firstly, this project focused only on the perspective of SE-AN sufferers. This focus developed the preference of the opinion of people with SE-AN; although the study findings were less influenced by the prevailing professional standards, they were acknowledged as the context in which the study occurred. However, Charmaz (2006) argued for the possibility of using a multidimensional view in the data gathering, I considered this limitation not as problematic, regarding the non-claim of the absolute truth as a finding, but rather it claims a deeper understanding and a greater insight into the phenomena that occurred.

Secondly, all but one of the interviews were carried out at a single SEDU, despite the fact that all the women who participated were free to choose where to have the interview. Sandy was the exception, preferring to use 'Skype'. Given this, the interview location could potentially create a power imbalance between me as a researcher, and the women SE-AN sufferers.

The third limitation, which many might identify, was the small sample size. However, within such a rich and in-depth qualitative study this is not unusual as it seemed that the saturation point had been achieved. Ideally, more data could have been gathered across other units, or across a longer time period, however, owing to time and resource considerations this was not feasible. Working with a small sample size could create concerns when attempting to generalise the results to other SE-AN patients; however, constructing a grounded theory study is not about the statistical generalization of the results, or the representation of the population

(Charmaz, 2006, p 101). The data emerged, revealed the possibilities in the approach for an improvement of the QoL of SE-AN people. The fourth limitation concerned the use of the feminist approach; and it is acknowledged that the incidence rates of AN among males was less than 1 person/100.000 per year (Smink et al., 2012). As a result of this figure, recruiting male SE-AN patients may prove difficult, at the moment of research, no SE-AN male took advantage of the SEDU (See also: Section 4.4: Sampling and recruitment). The fifth limitation is the use of a single methodology. The possibility of a mixed-method approach may have provided further data. The limitation concerned the use of a qualitative approach in general and the use of grounded theory specifically. In this matter, it was worthwhile to study number of appearances more accurately respecting the fact that findings concerned the suffering, which were rather of importance and of high influence of the QoL of SE-AN people. Then, the use of grounded theory appeared to be limiting regarding the fact that the researcher needs to have familiarity with the topics of research and thus, with the women researched, which was not a problem in this study. Nevertheless, such a familiarity is important as, without having the accurate knowledge of the researched group, it might be complicated to create significance in the results and recommendations the study delivered.

This brought me to the sixth limitation, that of researching my own patients. This choice specifically considered possible ethical issues regarding the fact that potential interviewees might be obliged to participate in the study because of the familiarity. Therefore I have arranged the following measures: I asked for ethical approval of two ethical committees. 1.) The permission to perform this study was requested of and granted at the University of Central Lancashire, Preston (UCLan) (Appendices: 2 - 2.1). And 2.) The approval was also given by the METC of the Erasmus Medical Centre, Rotterdam (Appendices: 3 - 3.1 - 3.2 - 3.3). Then, the issue also considered the accurateness of memo writing and the frequent debriefing with the supervisory team (See also: Section 13.3: Researching my own patient participants). Hence, before each interview, I informed the participants by letter, and I asked them verbally for permission to participate and submitted the informed consent document. As a seventh limitation, this study was carried out in only one country, situated in only one SEDU, and thus, comparing the findings regarding similarities and differences was not possible. The eighth limitation concerned the fact that ‘quality of life’ approaches are ideally carried out over longer periods of time, and by the inclusion of time, the women might possibly have been able to present more comparative constructs. Then, finally, during this project, I used a limited scope in the interference of SE-AN sufferers and the quality of life they experienced. In the use of a GT approach, I focused on the rich data generation in the development of the insights, which is conceptualised by the SE-AN patients’ perspectives of the lived quality of life experiences, until the theoretical maturation occurred. This process identified four core categories. However, testing the theory in the real world was not yet possible yet, though this is recommended in the determination of its usefulness and thus, the generalization of the data to other SE-AN patients (Glaser & Strauss, 1967; Charmaz, 2006). Nevertheless, with the development of this theory, I created substantive and practical applications with regards to the findings in the acknowledgement of the existence of a broader scope that refers to the quality of life, which already exists for people suffering from psychiatric problems. Nevertheless, the extant literature findings may provide the possibility of bridging this gap.

12.7 Thesis conclusion

In conclusion, this project provided a deeper insight into the quality of life experienced in people suffering from severe and enduring Anorexia Nervosa. Consequently, the theory provided new means of engaging SE-AN sufferers in their request for appropriate care and therapeutic alliance.

The rationale, as used in this study, arose from a sincere interest in previously used approaches in respect of this specific field of empirical research. With regards to the current findings, they potentially contribute to a better engagement between the health care professionals and their SE-AN patients. The findings strengthen previously-existing empirical data, and were comparable to the currently effective guidelines, as used in Western countries, the *Dutch Guidelines for Eating Disorders* (Zorgstandaard Eetstoornissen, 2017), the *Royal Australian and New Zealand Practice Guidelines* (Hay et al., 2014) and the *National Institute for Health and Care Excellence* (NICE, 2017).

The thesis approaches four theoretical categories, which are ‘Suffering, but not in silence’, ‘One step forward, one step backwards’, ‘Connective tissue’ and ‘Best friend, best enemy’. Together, they identify the social and psychological core effects that the individual may experience as a result of the influences on their quality of life due to the continuing condition of severe and enduring Anorexia Nervosa, and how this may affect their personality, the reality they experience, the communication issues they may suffer from, and finally, the alliance between people with the SE-AN condition and the eating disorder services.

The thesis then went on to illuminate the tension between the acceptance of the anorexic status versus the rejection of it, and the continual tension suggests a challenge for all those who are involved in the situation, that is, the patients, the professionals and other important people who are involved in the life of the patient. Hopefully, this is guided by the request for an adjusted paradigm in the treatment of SE-AN sufferers.

In addition, the study added a contribution to the novel insight regarding the evidence in terms of theoretical and empirical insights, by the use of the constructivist approach according to Charmaz (2006). Finally, the findings have contributed to new therapeutic perspectives, whereby SE-AN sufferers might benefit from more appropriate treatment in the future. In order to ensure the rigour of the research, the following chapter (Chapter 13) presents the self-reflection regarding being a researcher.

Chapter 13 Reflexivity

13.1 Introduction

In this final chapter, I specifically present the personal aspects of my role of a researcher in conducting this study project. Referring to Professor Karen Wright, my premier Director of Studies, a moment appeared when I was seriously struggling to clarify the data findings and to present them logically 'on paper'. As a result of this situation, I started to doubt myself and my ability in the personal journey that this research symbolises. Karen wrote to me with the following:

> *"But on a serious note - you can do this. I have every faith that you can push yourself that little bit further to do 'doctorate', because 'Dr ' is not a title that is handed out lightly!"*

This statement encouraged me so much, and through this I was even more determined to succeed in this project. In the following sections, I explain my reflexivity, and the importance of it in Grounded Theory.

13.2 Myself as a researcher

In daily practice, as a nurse specialist, I have interviewed the patients many times, mostly because of the screening process, or in conducting biographies as a part of the supportive research which is necessary for their treatment. At the start of this project, I imagined I would not have too much difficulty in conducting the interviews. However, during normal interviews, I realised that the setting needed to be slightly different when interviewing people with regards to my project, as this setting would possibly be coloured by the importance I attached to these moments because of the significance of it to me in terms of the doctorate. Suddenly I also had to deal with stringent rules, surrounding the process, such as the obligatory documents, which were necessary, because of the permission the women SE-AN patients had to give. In addition, I had to refer to the use of recording equipment to the participants and, although I did not experience any difficulties with this, it still had to be mentioned and considered, otherwise it may have been forgotten. I was also aware of the influence that my presence in the interviews might have on the women SE-AN patients (Gentles et al., 2014), and indeed, my supervisory team noticed an influence on the first recording. Certainly, I felt nervous, although I cannot remember exactly what kind of influences concerned me. I considered that I was impressed ‘by the moment’, since I was interviewing my first patient participant.

Nevertheless, since the research started, I was obliged to use a logbook, which was a built-in software function of MAXQDA. The logbook turned out to be very helpful and it enabled me to clear my mind, so that I would not forget any important insights. Furthermore, whilst I was focusing on one particular point during the interview, the logbook provided me with an overview at the end of the interview. As honestly as possible, I wrote down my doubts and insights, personal feedback, sometimes a few literature insights, and I interspersed these with relevant feedback from the supervisory team members. The logbook also provided me with a glimpse of the effort I was putting in during the project. I noted the duration of my working hours, sometimes realising that I was working a ‘double shift’, and I did this for a year, which finally took its toll on me in October 2018, when I became ill.

In this project, the scope of the reflexivity is not only described in the current chapter, but also throughout the research in terms of the GT approach, by means of defining my understanding, my position and my philosophical approach (Gentles et al., 2014). Indeed, I started this thesis by presenting my personal and professional motivations, supported by the insights of the process-focused approach of Visser (2014) (see Flowchart 1 in Chapter 1). One of the motives to which I was dedicated was Visser’s (2014) insight and, in responding to his approach, I *dived* into something that really interested me, and I have *found myself* in a state of fascinated involvement, and with this, I have *experienced* the most positive emotions. This research process has brought me to a deeper concentration, a deeper understanding, and better knowledge of the topic of this research. In my whole life, I have never learnt so well and so effectively as in this study.

Starting the project, I decided to take a 1-day course in operating MAXQDA (see Section 4.7: MAXQDA) at the Erasmus University in Rotterdam, in the Netherlands, which was run by Janine Evers. I did this course due to the fact that I am a novice in the field of research, and I was not aware of how certain software programs might benefit my study project. Janine Evers is a member of the board of KWALON, the Dutch platform for qualitative research[68]. After an intense day of hard work on the course, I learned how to use the program, and I became more aware of the common mistakes or misinterpretations that people often make in qualitative research. For this reason, taking the course turned out to be a worthy decision.

In the realisation that certain research processes, such as carrying out a GT methodology, is a rather lonely one, and realising that I am a foreign student, living in the Netherlands, but studying at the University of Central Lancashire, Preston, England, it is of importance to guarantee the reflexivity (Gentles et al., 2014; Charmaz, 2006). In order to meet such conditions, a frequent debriefing with the supervisory team was conducted, using Skype. In addition, these discussions were valuable in terms of the confidence given and the support received. During each session, a recording was made and these actions provided me with the complete process of the project with regards to openness, and gave me the feeling that I was not carrying out the whole project by myself.

Whilst processing the verbatim data, I offered the transcripts to my supervisory team, and they provided feedback on the transcripts. Often, the team criticised the language use, and the objectivity of the SE-AN patients. Furthermore, the supervisory team directed me into gaining a deeper understanding of the topics by inviting me to search for a deeper understanding. In

---

[68] http://www.kwalon.nl/organisatie

doing so, I provided my work with more transparency, rigour and openness in terms of the thinking styles and the decision-making (Gentles et al., 2014; Charmaz, 2006).

Furthermore, during the data analysis, as discussed in this thesis, I often referred to the 3-day meeting with my supervisory team, when we scrutinised the data at the start of the analysis process. This event proved invaluable in terms of the major effects it had in reaching a theoretical momentum. Looking back, I needed *this rehearsal*, which was conducted by highly experienced scholars, and I learnt so much from this meeting. The meeting with my supervisory team made me realise that I lacked experience regarding my first interpretation of scrutinising data, and this experience helped to analyse my skills, in terms of active learning, which, in turn, is obviously related to the constructivist approach (Charmaz, 2006). In hindsight, I am still very grateful for this supervisory event.

13.3 Researching my own patient participants

At the start of this project, I enthusiastically and extensively informed all the participating women SE-AN sufferers and all my colleagues about this research. Everyone I informed reacted positively, referring to the importance of the topic, and also, to the possibility of improving our current treatment that is offered. As previously described in this thesis (see Section 2.5: The SEDU as seen from a personal perspective), it is the SEDU that provides treatment and care for those suffering from SE-AN. At the start of this study, it was clear that I would mostly have to interview my own patients, as a result of the fact that I am generally the professional who offers these people a treatment, since this is related to my job in the in-patient setting of the SEDU. Nevertheless, Charmaz (2006) strongly stated that familiarity with the participants was an advantage and, therefore, I took account of the possible side effects of familiarity by arranging professional specialist psychological help, if needed. I informed my team of this possible request, by involving them in frequent debriefing sessions regarding the progress of the research. However, it turned out that the professional help was not needed, even though one of the women stated that she was struck by the impact the interview had had on her. Mariah, the concerned participant, was, however, of the opinion that it was not the impact of the interview itself, but rather, the strong impact that the eating disorder effectively had on her life, a realisation that was provoked by the interview. She concluded that this feeling had always been there, but it was this conclusion that made her feel very sad. Overall, I determined that had I not been as familiar with the women SE-AN sufferers, I would not have reached such an in-depth understanding of the women for this project.

A laugh and a tear occurred in many of the interviews, despite the vulnerability of the women. I remember the women using their quirky humour, which was full of self-deprecation, while, at the same time, challenging their own condition. In this way, they really could have a good laugh about their personal accounts, and most of the women were still able to take an objective view of their own, sometimes amusing, behaviour as influenced by the eating disorder. And regarding the fact that I knew some of the women very well, I felt the space to share such entertaining moments. However, in general, the interviews led to a deeper understanding of their personal situations, by sharing the intensively moments, the women felt that they were being taken seriously and were being ‘heard’. It felt as if this was their moment to discuss their ideas, possibilities and impossibilities regarding their situation.

Finally, in remembrance of Sandy, who sadly died during the process of this research, I owe her so much. She offered me an insight into her deep suffering, and not forgetting the total support of her loved ones and the devotion of the professionals. She presented friendship. I complete this chapter, and thus this thesis, with the following words:

Sandy, ‘fare thee well’.

References

Abbate-Dage, G., Amianto, F., Delsedime, N., De-Bacco, C. & Fassino, S. (2013). Resistance to treatment and change in anorexia nervosa: a clinical review. *Biomedical Central Psychiatry,* Vol. 13: p 294.

Ahmed, A. (2008). Ontological, Epistemological and Methodological assumptions: Qualitative versus Quantitative. Faculty of Education, Helwan University, Egypt. School of Education & Lifelong Learning, University of Exeter, UK.

Agras, W.S., Fitzsimmons-Craft, E.E. & Wilfley, D.E. (2017). Evolution of cognitive–behavioral therapy for eating disorders*. Behaviour Research and Therapy.* Vol. 88: pp 26-36.

American Psychiatric Association (2014). *Beknopt overzicht van de criteria (DSM-5). Nederlandse vertaling van de Desk Reference to the Diagnostic Criteria from DSM-5 ®.* Amsterdam, Nederland: Boom Uitgeverij.

Amianto, F., Northoff, G., Abbete Daga, G., Fassino, S. & Tasca, G.A. (2016). Is Anorexia Nervosa a Disorder of the Self? A Psychological Approach. *Frontiers in Psychology.* Vol. 7**:** p 849.

Arkell, J. & Robinson, P. (2008). A pilot case series using qualitative and quantitative methods: biological, psychological and social outcome in severe and enduring eating disorder (anorexia nervosa). *International Journal of Eating Disorders,* Vol. 41(7): pp 650-656.

Austin, S. (2009). A perspective on the patterns of loss, lack, disappointment and shame encountered in the treatment of six women with severe and chronic anorexia nervosa. *Journal of Analytical Psychology,* Vol. 54(1): pp 61-80.

Baarda, B. (2014). *Dit is onderzoek. Handleiding voor kwantitatief en kwalitatief onderzoek.* (Second Edition). Groningen/Houten, Nederland: Noordhoff Uitgevers.

Bamford, B.H. & Mountford V.A. (2012). Cognitive behavioural therapy for individuals with longstanding anorexia nervosa: adaptations, clinician survival and system issues. *European Eating Disorders Review*, Vol. 20(1: pp 49-59.

Barbarich-Marsteller, N.C, Foltin, R.W. & Walsh, B.T. (2011). Does Anorexia Nervosa Resemble an Addiction? *Current Drug Abuse Reviews*, Vol. 4(3): pp 197-200.

Beauchamp, T. & Childress, J. (2012). *Principles of biomedical ethics.* New York, United States: Oxford University Press.

Becker, S., Bryman, A. & Ferguson, H. (2012). *Understanding research for social policy and social work. Themes, methods and approaches.* (Second Edition). Bristol, United Kingdom: The Policy Press.

Benini, L., Todesco, T., Frulloni, L., Dalle Grave, R., Campagnola, P., Agugiaro, F., Cusumano, C.D. & Gabbrielli Vantini, I. (2010). Esophageal motility and symptoms in restricting and binge-eating/purging anorexia. *Digestive Liver Diseases*, Vol. 42(11*)*: pp 767-772.

Berger, R. (2008). Review: Lewins, A. & Silver, C. (2007). Using Software in Qualitative Research: A Step-by-Step Guide [18 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, Vol.10(1), Art. 23, http://nbn-resolving.de/urn:nbn:de:0114-fqs0901235.

BIG register (2019). Ministerie van Volksgezondheid, Welzijn en Sport. Retrieved May 26, 2017, from https://www.bigregister.nl

Birmingham, C. & Treasure, J. (2010). *Medical management of Anorexia Nervosa,* (2nd edition). Cambridge, United Kingdom: Cambridge University Press.

Böhm, A. (2004). Theoretical Coding: Text analysis in Grounded Theory. In Flick, U., Kardorff, E. & Steinke, I. (Eds.). *A comparison to Qualitative Research.* (pp. 270-275). London, United Kingdom: SAGE Publications.

Bowen, G.A. (2008). Naturalistic inquiry and the saturation concept: a research note. *Qualitative Research*, Vol. 8: pp 137-152.

Brown, C. & Mehler, P.S. (2015). Medical complications of anorexia nervosa and their treatments: an update on some critical aspects. *Eating and Weight Disorders,* Vol. 20(4): pp 419- 425.

Bruyninckx, E. & Mortelmans, D. (1999). Kwaliteit van leven en gezondheidszorg in verandering. *Tijdschrift voor Sociologie,* Vol. 20(1): pp 25-50.

Burckhardt, C.S. & Anderson, K.L. (2003). The Quality of Life Scale (QOLS): reliability, Validity and Utilization. *Health Quality of Life Outcomes.* Vol. 1(1): p 60.

Burger, H. & Hofman, A. (2005). Klinische epidemiologie. In Van der Meer J., Stehouwer C.D.A. *Interne Geneeskunde.* (Dertiende druk). Houten, Nederland: Bohn Stafleu van Loghum.

Burton, N. (2012). The Meaning of Madness. 'Mental illness' is more than just illness. Retrieved January 5, 2019, from https://www.psychologytoday.com/us/blog/hide-and-seek/201209/themeaning-madness.

Busschbach, J.J. (1994). *De validiteit van QALY's.* Arnhem, Nederland: Gouda Quint.

Busschbach, J.J. (1997). The measurement of quality of life in pharmacoeconomic investigations. *Ziekenhuisfarmacie,* Vol. 13(52): p 4.

Cambridge Dictionary. (2019). Madness. Retrieved July 9, 2018, from https://dictionary.cambridge.org/dictionary/english/madness.

All About Philosophy. (2018). Carthesian Dualism. Retrieved November 28, 2018, from https://www.allaboutphilosophy.org/cartesian-dualism-faq.htm.

Charmaz, K. (1990). 'Discovering' chronic illness: using grounded theory. *Social Science & Medicine,* Vol. 30(11): pp 1161-1172.

Charmaz, K. (1996). The search for Meanings - Grounded Theory. In Smith, J.A., Harré, R. & Van Langenhove, L. (Eds.). *Rethinking Methods in Psychology*. pp. 27-49. London, United Kingdom: SAGE Publications.

Charmaz, K. (2000). *Objectivist and Constructivist Methods.* In *The SAGE Handbook of Qualitative Research.* Edited by Denzin, N.K. & Lincoln, Y. (Third Edition). United States, California: Thousand Oaks.

Charmaz, K. (2006). *Constructing grounded theory. A practical guide through qualitative analysis*. London, United Kingdom: Sage Publications.

Charmaz, K. (2008). Grounded Theory as an emergent Method. In Hesse-Biber, S.N. & Leavy, P. *Handbook of Emergent Methods*. pp. 155-172. New York, United States: Guilford Press.

Charmaz, K. (2008). Constructionism and the Grounded Theory. In Holstein, J.A. & Gubrium, J.F. (Eds.), *Handbook of the Constructionist Research*, pp. 397-412. New York, United States: The Guilford Press.

Charmaz, K. (2012). The power and potential of Grounded Theory. *A Journal of the BSA Medical Social Group,* Vol. 6(3): p 12.

Charmaz, K. (2007). Grounded Theory. Making discoveries throughout the analysis of data. Retrieved May 28, 2018, from https://www.slideshare.net/clauditacar/grounded-theory-11679304.

Chiovitti, R.F. & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing,* Vol. 44(4): pp 427-435.

Conti, J.E. (2018). Recovering Identity from Anorexia Nervosa: Women's Constructions of Their Experiences of Recovery from Anorexia Nervosa Over 10 Years. *Journal of Constructivist Psychology,* Vol. 31(1): pp 72-94.

Coony, A. (2011). Rigour and Grounded Theory. *Nurse Research*, Vol. 18(4): pp 17-22.

Corbin, J. & Strauss, A. (2008). *The Basics Of Qualitative Research* (3rd Ed.). Los Angeles, United States, CA: Sage.

Crisp, A. (1968). Case report: Anorexia nervosa in an identical twin. *Post Graduate Medical Journal*, Vol. 9(4): p 86.

Crotty, M. (1998). *The Foundations of Social Research. Meaning and perspective in the research process.* (Reprinted 2015). London, United Kingdom: Sage Publications.

Culkin, A., Gabe, S.M., Peake, S.T. & Stern, J.M. (2012). A dangerous combination of binge and purge. *International Journal of Eating Disorders*. Vol. 45(2): pp 302-4.

De Boer, F. (2011). De Grounded Theory Approach: een update. *Kwalon,* Vol. 16(1): pp 25-33.

De Jong, A., Vandenbroele, H., Glorieux, M., de Maesschalk, L. & Visser, M. (2008). *Inleiding wetenschappelijk onderzoek voor het gezondheidsonderwijs.* Maarssen, Nederland: Elsevier/de Tijdstroom.

De la Rie, S.M., Noordenbos, G. & Van Furth, E.F. (2005). Quality of life and eating disorders. *Quality of life research*, Vol. 14(6); pp 1511-1522.

De Vries, S. & Weijers, R. (2017). 5 typen bias in data & analytics. Retrieved June 8, 2017, from http://www.cmotions.nl/5-typen-bias-data-analytics/.

Denzin, N.K. & Lincoln, Y.S. (2005). *The SAGE Handbook of Qualitative Research.* (Third Edition). United States, California: Thousand Oaks.

Diener, E., Suh, E.M., Lucas, R.E. & Smith, H.L. (1999). Subjective well-being: Three decades of progress. *Psychological Bulletin.* Vol. 125(2): pp 276-302.

Dolan, B. & Gitzinger, I. (1994). *Why Women?* London, United Kingdom: The Athlone Press Ltd.

Easter, M.M. (2012). “Not all my fault”: Genetics, stigma, and personal responsibility for women with eating disorders. *Social Science and Medicine,* Vol. 75(8): pp 1408-1416.

Elzakkers, F.F.M., Danner, U.N., Hoek, H.W. & van Elburg, A.A. (2016). Mental capacity to consent to treatment in anorexia nervosa: explorative study. *British Journal of Psychiatry Open,* Vol. 2(2): pp 147-153.

Elzakkers, F.F.M. & van Delden, H. (2018). Ethische vraagstukken. *Handboek Eetstoornissen.* Utrecht, Nederland: De Tijdstroom.

Elzakkers, F.F.M. (2016). Altrecht eetstoornissen Rintveld. Wilsbekwaamheid en Anorexia Nervosa. Retrieved May 4, 2018, from https://www.altrecht.nl/wp content/uploads/2015/12/Brochure-Wilsbekwaamheid-WEB.pdf

Engel, S.G., Wittrock, D.A., Crosby, R.D., Wonderlich, S.A, Mitchell, J.E. & Kolotkin, R.L. (2006). Development and psychometric validation of an eating disorder-specific health-related quality of life instrument. *International Journal of Eating Disorders*, Vol. 39(1): pp 62-71.

Evans, G.L. (2013). A Novice Researcher’s First Walk through the Maze of Grounded Theory: Rationalization for Classical Grounded Theory. *Grounded Theory Review: An International Journal,* Vol. 6(1): pp 1-17.

Evers, J. (2009). Over kwalitatieve data-analyse valt nog veel te schrijven! *Kwalon,* Vol. 41*,* (14): p 2.

Espeset, E.M., Nordbø, R.H., Gulliksen, K.S., Skårderud, F., Geller, J. & Holte, A. (2011). The concept of body image disturbance in anorexia nervosa: an empirical inquiry utilizing patients’ subjective experiences. *Eating Disorders,* Vol. 19(2): pp 175- 193.

FACT Nederland (2019). Wat is F-ACT? Retrieved May 26, 2017, from https://www.f-actnederland.nl/wat-is-f-act/

Fairburn, C.G. (2008). *Cognitive Behavior Therapy and Eating Disorders.* New York, United States & London, United Kingdom: The Guilford Press.

Filosofie (2019). René Descartes. Retrieved November 24, 2018, from https://www.filosofie.nl/renedescartes/index.html

Fisher, C.A., Skocic, S., Rutherford, K.A. & Hetrick, S.E. (2018). Family therapy for those diagnosed with anorexia nervosa. *Cochrane Library, Cochrane Database of Systematic Reviews.* Published by John Wiley & Sons Ltd. Issue 10.

Fox, J.R.E. & Diab, P. (2015). An exploration of the perceptions and experiences of living with chronic anorexia nervosa while an inpatient on an eating disorders unit: An Interpretative Phenomenological Analysis (IPA) study. *Journal of Health Psychology,* Vol. 20(1): pp 27-36.

Fundamental Facts about Mental Health. (2015). Retrieved April 24, 2017, from https://www.mentalhealth.org.uk/sites/default/files/fundamental-facts-15.pdf

Gasson, S. (2004). Rigor in Grounded Theory Research: An Interpretive Perspective On Generating Theory From Qualitative Field Studies. In Whitman, M. E. & Woszczynski, A.B. (Eds.). *The Handbook of Information Systems Research*. New York, United States: Igi Global.

GGZ Altrecht. (2019). Eetstoornissen Rintveld. Retrieved April 3, 2017, from https://www.altrecht.nl/zorgeenheid/eetstoornissen-rintveld/

GGZ Amarum Expertisecentrum Eetstoornissen. (2019). Behandelmogelijkheden. Retrieved April 3, 2017, from http://www.amarum.nl/site/Behandelmogelijkheden/

GGZ Kwaliteitsstatuut. (2019). Retrieved May 26, 2017, from https://www.ggzkwaliteitsstatuut.nl

GGZ Rivierduinen Eetstoornissen Ursula. (2019). Retrieved April 3, 2017, from https://www.rivierduinen.nl/eetstoornissen

GGZ Standaarden. (2017). Zorgstandaarden Eetstoornissen. Retrieved September 5, 2018, from https://www.ggzstandaarden.nl/zorgstandaarden/eetstoornissen/visie-op-zorg-gezondheid-alsperspectief

Guba, E.G. & Lincoln, Y. (1994). Competing paradigms in qualitative research. In Denzin, N. & Lincoln, Y. (Eds.), *The SAGE Handbook of Qualitative Research* (pp. 105-117). London, United Kingdom: Sage Publications.

Gobbens, R.J.J., Luijkx, K.G., Wijnen-Sponselee, M.T. & Schols, J.M.G.A. (2010). In search of an Integral conceptual definition of frailty. Opinions of experts. *Journal of the American Medical Directors Association,* Vol. 11(5): pp 338-343.

Goffman, E. (1963). in Van Weeghel, J., Pijnenborg, M., Vant Veer, J. & Kienhorst, G. (2016). *Handboek destigmatisering bij psychiatrische aandoeningen.* Bussum, Nederland: Uitgeverij Coutinho.

Goss, K. & Allan, S. (2009). Shame, pride and eating disorders. *Clinical Psychology Psychotherapy,* Vol. 16(4): pp 303-216.

Gowers, S., Norton, K., Halek, C. & Crisp, A.H. (1994). Outcome of patients' psychotherapy in a random allocation treatment study of anorexia nervosa. *International Journal of Eating Disorders,* Vol. 15(2): pp 165-177.

Glaser, B.G. & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research.* New York, United States: Aldine de Gruyter.

Glaser, B.G. (1978). *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory.* Mill Valley, CA, United States: Sociology Press.

Glaser, B.G. (1992). *Basics of Grounded Theory Analysis: Emergence v Forcing.* Mill Valley, CA, United States: Sociology Press.

Glaser, B.G. (1998). *Doing Grounded Theory. Issues and Discussions.* Mill Valley, CA, United States: Sociology Press.

Glaser, B.G. (2007). All is Data. *Grounded Theory Review. An International Journal*, Vol. 2(6): pp 1-22.

Griffiths, S., Mond, J.M., Murray, S.B. & Touyz, S. (2015). The prevalence and adverse associations of stigmatization in people with eating disorders. *International Journal of Eating Disorders,* Vol. 48(6): pp 767-774.

Gynnild, A. (2011). Book Review: Grounded Theory: A practical guide (Birks & Mills, 2011). *The Grounded Theory Review,* Vol. 10(3): pp 63-66.

Hannes K.(2010). Het Qualitative Assessment and Review Intrument (QARI) ter ondersteuning van synthesen van kwalitatief onderzoek. *Kwalon,* Vol. 15 (3): pp 35-44.

Harbottle, E.J., Birmingham, C.L. & Sayani, F. (2008). Anorexia nervosa: a survival analysis. *Eating and Weight Disorders.* Vol. 13(2): pp 32-34.

Harris, E.C. & Barraclough, B. (1998). Excess mortality of mental disorder. *British Journal of Psychiatry,* Vol. 173: pp 11- 53.

Hay, P., Chinn, D., Forbes, D., Madden, S., Newton, R., Sugenor L., Touyz, S. & Ward, W. (2014). Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders. *Australian & New Zealand Journal of Psychiatry,* Vol. 48(11): pp 1-62.

Heenan, M.C. (1995). Feminist Psychotherapy – A Contradiction in Terms? *Feminism & Psychology,* Vol. 5(1): pp 112-117.

Heenan, M.C. (1996). ‘Women, Food & Fat- Too many cooks in the Kitchen?’, in Burman, E., Aitken, G., Alidred, P., Allwood, R., Billington, T., Goldberg, B., Gordo Lopez, A.J., Heenan, M.C,. Marks, D. & Warner, S. *Challenging Women: Psychology’s Exclusions, Feminist Possibilities.* Milton Keynes: Open University Press.

Heenan, M.C. (2005). ‘Looking in the fridge for feelings’. Psychodynamics of Consumer culture, in Davidson, J., Bondi, L. & Smith, M. *Emotional Geographies.* Burlington. Great Britain. Ashgate Publishing: VT & Aldershot. pp. 147-160.

Heenan, M.C. (2005). A feminist psychotherapeutic approach to working with women who eat compulsively. *Counseling and Psychotherapy Research, 5* (3): pp 1-19.

Hepworth, J. (1999). *The social construction of anorexia nervosa.* London, United Kingdom: Sage Publications.

Hoek, H.W. (1993). Review of the epidemiological studies of eating disorders. *International Review of Psychiatry,* Vol. 5(1): pp 61-74.

Howarth, M.L. (2012). Being believed and believing in: The impact of delegitimation on person-centred care for people with chronic back pain. PhD Thesis. School of Nursing, Midwifery and Social Work. College of Health and Social Care, University of Salford, Salford, United Kingdom.

Ioannidis J.P.A. (2016) Why Most Clinical research Is Not Useful. *PLoS Medicine,* Vol 13(6): e1002049.

Janssen, H., de Jong, M. & Knol, E. (2017). Samen sterk op weg naar herstel. Een onderzoek bij stichting Missionpuppy Nederland naar assistentiehonden voor mensen met psychische problematiek. In opdracht van de Hogeschool Utrecht, Nederland. Faculteit Maatschappij en Recht.

Joaquin, (2017). What is Self-Actualization? A Psychologist’s Definition [+Examples]. Retrieved February 2, 2019, from https://positivepsychologyprogram.com/self-actualization/

Kalfoss, M., Low, G. & Molzahn A. (2008). The suitability of the WHOQOL-BREF for Canadian and Norwegian older adults. *European Journal of Ageing,* Vol. 5(1): pp 77-89.

Kelly, A.C. & Tasca, G.A. (2016). Within-persons predictors of change during eating disorder treatment: an examination of self-compassion, self- criticism, shame, and eating disorder symptoms. *International Journal of Eating Disorders,* Vol. 49(7): pp 716-722.

Keshaviah, A., Edkins, K., Hastings, E.R., Krishna, M., Franco, D.L., Herzog, D.B., Thomas, J.J., Murray, H.B. & Eddy, K.T. (2014). Re-examining premature mortality in anorexia nervosa: a meta-analysis redux. *Comprehensive Psychiatry,* Vol. 55(8): pp 1773-1784.

Klaverwijden, C. (2010). Wat kan humanistiek van feminisme leren? Gluren bij de buren. *Partage,* Vol. 1(1): pp 5-13.

Kuiper, C., Verhoef, J., de Louw, D., Cox, K. (2008). *Evidence based practice voor paramedici: Methodiek en toepassing.* 2 dr. Den Haag, Nederland: Uitgeverij LEMMA. pp. 19-21, 40.D.

Lambregts, J., Projectgroep, V. &V.N. 2020, Grotendorst, A. (2012) Beroepsprofiel Verpleegkundig specialist. Retrieved March 6, 2017, from http://www.venvn.nl/Portals/1/Nieuws/Ouder%20dan%202010/4_profiel%20verpleegkundig%0specialist_def.pdf.

Le Grange, D. (2007). The Maudsley Family-based Treatment of Adolescent Anorexia Nervosa. *World Psychiatry,* Vol. 4(3): pp 142-146.

Le, L.K., Barendregt, J.J., Hay, P. & Mihalopoulos, C. (2017). Prevention of eating disorders: A systematic review and meta-analysis. *Clinical Psychology Review,* Vol. 12: pp 46-58.

Lewis, J. (2017). Feminism: Ideas, Beliefs, and Movements. Retrieved June 12, 2017, from https://www.thoughtco.com/what-is-feminism-3528958

Li, N. (2014). Using Software in Qualitative Research: A Step-by-Step Guide (2nd ed.) – A Review. Retrieved February 9, 2019, from https://nevilleliresearch.weebly.com/uploads/3/1/2/8/31284985/using_software_in_qualitative_research_-_a_step_by_step_guide.pdf

Link, B.G. & Phelan, J.C. (2001). Conceptualizing stigma. *Annual Review of sociology,* Vol. 27: pp 363-385.

Lock, J. & Fitzpatrick, K. (2009). Anorexia Nervosa. *British Medical Journal Clinical Evidence.* Published online March 10.

Marcus, D. & Wiener, M. (1989). Anorexia nervosa reconceptualized from a psychosocial transactional perspective. *The American Journal of Orthopsychiatry,* Vol. 59(3): p 346.

McIntosh, V.V., Jordan, J. & Bulik, C.M. (2010). Specialist supportive clinical management for anorexia nervosa. *In The treatment of eating disorders: A Clinical Handbook* (Eds. M. Grilo & J.E. Mitchell), pp.108-129. New York, United States: Guilford Press.

McIntosh, V.V., Jordan, J., Luty, S.E., Carter, F.A., McKenzie, J.M., Bulik, C.M. & Joyce, P.R. (2006). Specialist supportive clinical management for anorexia nervosa. *International Journal of Eating Disorders,* Vol. 39(8): pp 625-632.

McLeod, S. A. (2008). Self concept. Retrieved February 9, 2019, from www.simplypsychology.org/selfconcept.html.

Merton, R.K. (1948). The Self-Fulfilling Prophecy. *The Antioch Review,* Vol. 8*(*2): pp 193-210.

Miles, A.M., Huberman, M.B. & Saldana, J. (2013). *Qualitative Data Analysis, a Methods Sourcebook.* Ed. 3. Los Angeles, London, New Delhi, Singapore, Washington DC. United States: Sage Publications. pp. 275- 322.

Mills, J., Bonner, A. & Francis, K. (2006). The development of constructive theory. *International Journal of Qualitative Methods,* Vol. 5(1): pp 1-10.

Molnos, A. (1998): A psychologist's harvest: A to Z of Clinical Practice and Theoretical Issues with Special Reference to Brief Forms of Psychoanalytically Based Treatment. Retrieved November 17, 2018, from http://fox.klte.hu/~keresofi/psyth/a-to-z entries/blame_attribution.html.

Montesquieu Instituut (2019). Van Wetenschap naar samenleving. Karl Marx en Friedrich Engels. Een spook waart door Europa – Het spook van het communisme. Retrieved June 26, 2017, from https://www.montesquieuinstituut.nl/id/viv1o0h1kpqo/karl_marx_en_friedrich_engels.

Morse, J.M., Barret, M., Mayan, M., Olson, K. & Spiers, J. (2002). Verification strategies for establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods,* Vol. 1(2): pp 13-22.

Munro, C., Thomson, V., Corr, J., Randell, L., Davoes, J.E., Gittoes, C., Honeyman, V. & Freeman C.P. (2014). A new service model for the treatment of severe anorexia in the community: the Anorexia Intensive Treatment Team. Psychiatric Bulletin, Vol. 3(5): pp 220-225.

My Pro Ana (2019). Forums. Retrieved August 13, 2018, from https://www.myproana.com/index.php/topic/404087-childlike-behavior/.

Newell, C. (2007). Recovery in Anorexia nervosa: The struggle to develop a new identity. A thesis submitted in partial fulfillment of the requirements of the Bournemouth University for the degree of Doctor in Philosophy. United Kingdom.

Neychev, V. & Borruso, J. (2015). Bowel ischemia and necrosis in anorexia nervosa: A case report and review of the literature. *International Journal Surgery Case Report,* Vol. 8, pp 141-143.

National Institute for Clinical Excellence Eating Disorders (NICE) (2017). Recognition and Treatment. London, National Institute for Clinical Excellence. Retrieved June 10, 2017.

Noordenbos, G., Oldenhave, A., Terpstra, N. & Muschter, J. (2000). Kenmerken en behandelingsgeschiedenis van patiënten met chronische eetstoornissen. *Tijdschrift voor Psychiatrie,* Vol. 42(3): pp 145-155.

Noordenbos, G. (2010). Ontbrekende consensus over behandeldoelen en herstelcriteria voor eetstoornissen. *De Psycholoog*, pp 36-44.

Nordbø, R.H.S., Espeset, E.M.S., Gulliksen, K.S., Skårderud, F. & Holte, A. (2006). The Meaning of Self- Starvation: Qualitative Study of Patients' Perception of Anorexia Nervosa. *International Journal of Eating Disorders,* Vol. *39*(7): pp 556-564.

Nunn, A. (2009). Eating Disorder and the Experience of Self: An Interpretative Phenomenological Analysis. A Thesis submitted in partial fulfilment of the requirement of the University of Hertfordshire for the degree of Doctor of Clinical Psychology. United Kingdom.

Olsen, A. (2013). The Theory of Self-actualization. Mental illness, creativity and art. Theory and Psychopathology. Retrieved November 17, 2018, from https://www.psychologytoday.com/us/blog/theory-and-psychopathology/201308/the-theory-self-actualization.

Pantilat, S. (2008). Beneficence vs. Nonmaleficence. Retrieved February 2, 2019, from http://missinglink.ucsf.edu/lm/ethics/content%20pages/fast_fact_bene_nonmal.htm.

Papert, S. on Piaget, J. (1999). *Time magazine's special issue on "The Century's Greatest Minds."* 3, p 105.

Patel, P. (2016). A study of self-concept of the 11th standard students of Gandhinagar District in relation to certain variables. *International Journal of Social Impact,* Vol. 1(2): pp 82-89.

Patton, M.Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Service Research,* Vol. 34 (5, part 2): pp 1189-1208

Pawluck, D.E. & Gorey, K.M. (1998). Secular trends in the incidence of anorexia nervosa: integrative review of population-based studies. *International Journal of Eating Disorders,* Vol. 23(4): pp 347-352.

Pigou, A.C. (1920). *The Economics of Welfare.* London, United Kingdom: Macmillian and Co.

Poelman, T. (2015). Aan welke criteria moet kwalitatief onderzoek voldoen? *Minerva,* Vol. 14(2): p 24.

Polit, F.P., Beck, C.T., Loiselle, C.G. & Profetto-McGrath, J. (2011). *Canadian Essentials of Nursing Research. (Third Edition).* Lippincott Wilkins. Philadelphia, Baltimore, New York, London, Buenos Aires, Hong Kong, Sydney, Tokyo: Wolters Kluwer Health.

Puhl, R., Suh, Y. (2015). Stigma and eating and weight disorders. *Current Psychiatry Reports,* Vol. 17(3): p 552.

Ramalho, R., Adams, P., Huggard, P. & Hoare, K. (2015). Literature Review and Constructivist Grounded Theory Methodology. *Forum: Qualitative Sozialforschung / Qualitative Social Research,* Vol. 16(3) Art. 19.

Rand, A. (2018). Introduction to Objectivism. Retrieved May 1, 2017, from https://www.aynrand.org/ideas/philosophy#inrand'swords-1.

Robinson, P.H. (2009). *Severe and Enduring anorexia nervosa: Management of complex presentations of anorexia nervosa and bulimia nervosa.* West Sussex, United Kingdom: Wiley.

Robinson, P.H., Kukucsa, R., Guidetti, G. & Leavey, G. (2015). Severe and Enduring Anorexia nervosa (SEED-AN): A qualitative Study of Patients with 20+ Years of Anorexia nervosa. *European Eating Disorders Review,* Vol. 23(4): pp 318-326.

Robinson, P.H. (2014). Severe and enduring eating disorders: recognition and management. *Advances in Psychiatric Treatment,* Vol. 20(6): pp 392-401.

Rollins, N. & Piazza, E. (1981). Anorexia nervosa: A quantitative approach to follow-up. *Journal of the American Academy of Child Psychiatry,* Vol. 20: pp 167-183.

Roux, H., Chapelon, E. & Godart, N. (2013). Epidemiology of anorexia nervosa: A review. *Encephale,* Vol. 3(2): pp 85-93.

Rys, B. (2005). Eetgewoonten en eetstoornissen in historisch perspectief. *Rol en Samenleving,* Vol. 44: pp 4-8.

Sackett, D.L., Rosenberg, W.M., Gray, J.A., Haynes, R.B. & Richardson, W.S. (1996). Evidence based medicine: What it is and what it isn't. *British Medical Journal*, Vol. 312: pp 71-72.

Santonastaso, P., Ferrara, S. & Favaro, A. (1999). Differences between binge eating disorder and non-purging bulimia nervosa. *International Journal of Eating Disorders,* Vol. 25(2): pp 215-218.

Schalkwijk F. (2012). Schaamte in psychotherapie. *Tijdschrift voor Psychotherapie,* Vol. 38 (5): pp 368-380.

Shenton, K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information,* Vol. 22: pp 63-75.

Silverman, D. (2011). *Qualitative Research.* (3th Edition). London, United Kingdom: Sage Publications.

Singh, S. & Estefan, A. (2018). Selecting a Grounded Theory Approach for Nursing Research. *Global Qualitative Nursing Research,* Vol. 5: pp 1-9.

Smaling, A. (2010). Constructivisme in soorten. *KWALON,* Vol. 15**(**1): pp 20-30.

Smink, F.R.E., Van Hoeken, D. & Hoek, H.W. (2012). Epidemiology of Eating Disorders: Incidence, Prevalence and Mortality Rates. *Current Psychiatry Report,* Vol. 14(4): pp 406-414.

Steinhausen, H. (2002). The outcome of anorexia nervosa in the 20th century. *American Journal of Psychiatry*, **Vol.** 59: pp 1284-1293.

Stewart, M.C., Keel, P.K. & Schavio, R.S. (2006). Stigmatization of anorexia nervosa. *International Journal of Eating Disorders,* Vol. 39(4): pp 320-325.

Strauss, A.L. (1987). *Qualitative Analysis for Social Scientists.* Cambridge University Press. United Kingdom.

Strauss, A.L. & Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. London, United Kingdom: Sage Publications.

Strauss, A.L. & Corbin, J. (1998) *Basics of Qualitative Research – Techniques and Procedures for Developing Grounded Theory.* (2nd Edition). CA, United States: Sage Publications.

Gentles, S.J., Jack, S.M., Nicolas, D.B. & McKibbon, K.A. (2014). A Critical approach to reflexivity in Grounded Theory. *The Qualitative Report*, Vol. 19(25): pp 1-14.

Striegel-Moore, R.H., DeBar, L., Wilson, G.H., Dickerson, J., Rosseli, F., Perrin, N., Lynch, F. & Kreamer, H.C. (2008). Health services use eating disorders. *Psychological Medicine,* Vol. 38(10): pp 1465-1474.

Strober, M. (2004). Managing the chronic, treatment-resistant patient with anorexia nervosa. *International Journal of Eating Disorders,* Vol. 36(3): pp 245-255.

Strober, M. (2010). The Chronically Ill Patient with Anorexia Nervosa, Developemnt, Phenomenology, and Therapeutic Considerations. In Grilo, C.M. & Mitchell, J.E. *The Treatment of Eating Disorders.* New York, United States: Guilford Press.

Strober, M., Freeman, R. & Morrel, W. (1997). The long-term course of severe anorexia nervosa in adolescents: Survival of analysis of recovery, relapse and outcome predictors over 10-15 years in a prospective study. *International Journal of Eating Disorders,* Vol. 22(4): pp 339-360.

Tamboer, J.W.I. (1989) in Cox, K., de Louw, D., Verhoef, J., Kuiper, C. (2005). *Evidence – Based Practice voor Verpleegkundigen. Methodiek en Implementatie.* Utrecht, Nederland: Uitgeverij Lemma BV.

Tchanturia, K., Lounes, N. & Holttum, S. (2014). Cognitive remediation in anorexia nervosa and related conditions: a systematic review. *Eating Disorders Review,* Vol. 22(6): pp 454-62.

Ten Have, H.A.M.J., ter Meulen, R.H.J. & van Leeuwen, E. (2009). *Medische ethiek*. Houten/Diegem, Nederland: Bohn Stafleu van Loghum.

Tenwolde, A. (2002). Lichamelijke aspecten. In Vandereycken W., Noordenbos G. (red.). *Handboek Eetstoornissen,* Utrecht, Nederland: De Tijdstroom.

Thoman, D.B., Smith, J.L. & Silvia, P.J. (2011). The resource replenishment function of interest. *Social Psychological and Personality Science,* Vol. 2*:* pp 6592-6599.

Theofilou, P. (2013). Quality of Life: Definition and Measurement. *Europe's Journal of Psychology,* Vol. 9(1): pp 150-162.

Thornton, L.M., Welch, E., Munn-Chernoff, M.A., Lichtenstein, P. & Bulik, C.M. (2016). *Suicide Life Threatening Behaviours,* Vol. 46(5): pp 525-534.

Tierney, S. & Fox, J.R., (2009). Chronic anorexia nervosa: a Delphi study to explore practitioners' views. *International Journal Eating Disorders,* Vol. 42 (1): pp 62-7.

Tierney, S. & Fox, J.R. (2010). Living with the anorexic voice: a thematic analysis. *Psychology Psychotherapy,* Vol. 83(3): pp 243-254.

Touyz, S. & Hay, P. (2015). Severe and enduring anorexia nervosa (SE-AN): in search of a new paradigm. *Journal of Eating Disorders,* Vol. 3(1): p 26**.**

Touyz, S.D., Lacey, H., Hay, P., Smith, R., Maguire, S., Bamford, B., Pike, K.M. & Crosby, R.D. (2013). Treating severe and enduring anorexia nervosa: a randomized controlled trail. *Psychological Magazine,* Vol. 43(12): pp 2501-2511.

Townsend, M.C. (2009). *Verpleegkundige diagnostiek in de psychiatrie.* Maarssen, Nederland: Elsevier Gezondheidszorg.

Treasure, J., Murphy, T., Szmuckler, G., Todd, G., Gavan, K. & Joyce, J. (2001) The experience for severe mental illness: a comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology,* Vol. 36(7): pp 343-347.

Troop, N.A. & Redshaw, C. (2012). General shame and bodily shame in eating disorders: a 2.5-year longitudinal study. *European Eating Disorder Review,* Vol. 20(5): pp 373-380.

Vandereijcken, W., Hoogduin, C.A.L. & Emmelkamp, P.M.G. (2000). *Handboek Psychopathologie.* Deel 1. Basisbegrippen. Houten, Nederland: Bohn Stafleu Van Loghum.

Vandereijcken, W. (2006). Door dik en dun: Alles over anorexia en boulimia. Wormer, Nederland: Uitgeverij Inmerc.

Van Furth, E. (2013). Eetstoornissen in context. Oratie uitgesproken door Prof. Dr. Eric F. Van Furth bij de aanvaarding van het ambt van bijzonder hoogleraar op het gebied van eetstoornissen aan de universiteit van Leiden vanwege de Stichting Rivierduinen.

Van Hoogsteder, M. & Sbiti, A (2013). Werken in de langdurige zorg, Een diversiteitsperspectief. Kenniscentrum interculturele zorg. Retrieved June 6, 2017, from https://www.google.nl/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=2ahUKEwiotYSEZ_gAhUJJIAKHbeaACMQFjAAegQICBAC&url=https%3A%2F%2Flegacy.vgn.nl%2Fmedia%2Fdownload%2Findex%2Fmediaid%2F52a9c640ed097&usg=AOvVaw33mEx6mzHoGoY2V-jID3lq.

Van der Lans, J. (2009). De cliënt centraal – humanistische psychologie. Retrieved November 17, 2018, from https://www.canonsociaalwerk.eu/int/details.php?cps=13.

Van Deth in: Noordenbos, G. & Van Elburg, A. (2018) *Handboek Eetstoornissen.* Chapter 5: pp. 67-73. (Third Edition). Utrecht, Nederland: De Tijdstroom.

Van der Meer, J. & Steehouwer, C.D.A. (2007). Interne geneeskunde. Chapter 1, in Burger H., Hofman A. *Klinische epidemiologie.* Utrecht, Nederland: Bohn, Stafleu, van Loghum.

Van Mens-Verhulst, J. (2003). Diversiteit als sleutel tot vraagsturing in een gevarieerde samenleving. Over denkkader, handelingsprincipes en competentie. *Sociale interventie* Vol. 1: pp 25-34.

Van Mens-Verhulst, J. (2007). Intersectionaliteit, in vijf veronderstellingen (2007/2009). Retrieved April 24, 2017, from https://www.andragologie.org/uploads/andra_docs/alumnibijeenkomsten/ab_le_20071111_diersiteitenintersectionaliteit_vanmensverhulst.pdf

Van Son, G.E., Van Hoeken, D., Bartelds, A.I.M., Van Furth, E.F. & Hoek, H.W. (2006). Urbanisation and the incidence of eating disorders. *The British Journal of Psychiatry,* Vol. 189(12): pp 562-563.

Van Staa, A. & Evers, J. (2010). “Thick Analysis”: Strategie om de kwaliteit van kwalitatieve data analyse te verhogen. *KWALON,* Vol. 43(15): p 1.

Vellinga, A. & Van Melle, E. (2016). Moreel beleid: tijd voor ethische reflectie in de dagelijkse praktijk van de GGZ. *Tijdschrift voor Psychiatrie,* Vol. 58(3): pp 207-214.

Vickers, J. (2016). Exploring Engagement: a Grounded Theory Study of Young People’s Interactions with Healthcare Professionals. Ph.D. Thesis. School of Nursing, Midwifery and social work. College of Health and Social Care. University of Salford, United Kingdom.

Villerius, J. (2016). Emma wil leven. Retrieved April 3, 2017, from https://www.npostart.nl/3doc emma-wil-leven/22-11-2016/POMS_BNN_6035520 Visser, M. (2016). Factual Feminist: Vrouwen zijn helemaal niet zielig. *Vrij Nederland.* 09-01-2016.

Visser, C. (2014). Interesse als drijvende krachten achter ontwikkeling*. O&O,* Vol. 2: pp 18-22.

Vorst, J. (2009). Sociaal Constructivistisch Onderzoeksperspectief en Grounded Theory. Retrieved May 1, 2017, from http://joopvorst.com/downloads/Vorst%202009%20Sociaal%20%20constructivisme%20en%0Grouned%20Theory%20paper%20BSN.pdf.

Walley Hammell, K. (2002). Informing Client-Centred Practice through Qualitative Inquiry: Evaluating the Quality of Qualitative Research. *British Journal of Occupational Therapy,* Vol. 65(4): pp175-184.

Ware, J.E. Jr. & Gandek, B. (1998). Overview of the SF-36 Health Survey and the International Quality of Life Assessment (IQOLA) Project *journal of clinical epidemiology,* Vol. 51(11): pp 903–912.

Wekker, G. (2002). *Nesten bouwen op een winderige plek. Denken over gender en etniciteit in Nederland.* Utrecht, Nederland: Universiteit Utrecht.

Wekker, G. & Lutz, H. (2001). A wind-swept plain. A history of gender and ethnicity-thought in the Netherlands. In Botman M.. e.a. Eds. *Caleidoscopische Visies.* Amsterdam, Nederland.

Wentz, E., Gillberg, I.C., Anckarsäter, H., Gillberg, C. & Råstam, M. (2012). Somatic problems and self-injurious behaviour 18 years after teenage-onset anorexia nervosa. *European Child Adolescent Psychiatry,* Vol. 2(8): pp 421-432.

Wessels, R.H.A. (1997*). Informatie professional,* Vol. 3(1): pp 28-32.

Wheeldon, J. & Faubert, J. (2009). Framing experience: concepts Maps, Mind Maps, and Data Collection in Qualitative Research. *International Journal of Qualitative Methods,* Vol. 8(3): pp 68-83.

Williams, K.D., Dobney, T. & Geller, J. (2010). Setting the eating disorder aside: an alternative model of care. *European Eating Disorder Review,* Vol. 18(2): pp 90–96.

Williams, K., Williams, J. & Fox, J.R.E. (2015). Sense of self and anorexia nervosa: A grounded theory. *Psychology and Psychotherapy Theory Research and Practice*, Vol. 89(92): pp 1-18.

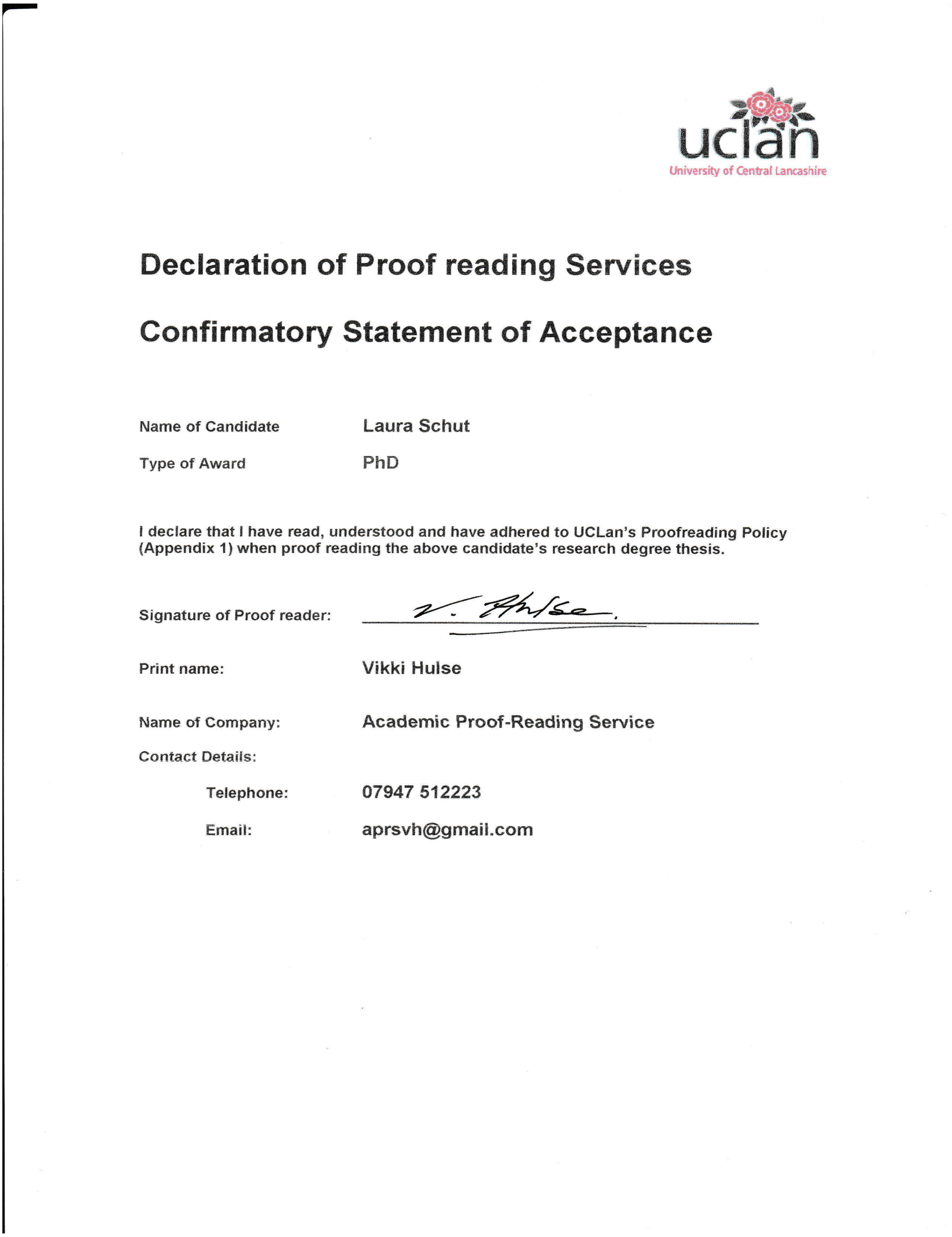
Willems, D. & Van Zwieten, M. (2004). Waardering van kwalitatief onderzoek. *Huisarts & Wetenschap,* Vol. 4(13): pp 631-635.

Wright, K.M. (2010) The therapeutic relationship – developing a new understanding for nurses and care workers within an eating disorder unit. *International Journal of Mental Health Nursing,* Vol. 19(3): pp 154–161.

Wright, K.M. (2013). *An interpretative Phenomenological Study of the Therapeutic Relationship between Women admitted to Eating Disorder services and their care workers.* Thesis submitted in partial fulfillment for the requirements for the Degree of Doctor of Philosophy at the University of Central Lancashire, United Kingdom.

Wonderlich, S., Mitchell, J.E., Crosby, R.D., Myers, T.C., Kadlec, K., Lahaise, K., Swan-Kremeier, L., Dokken, J., Lange, M., Dinkel, J., Jorgensen, M. & Schander, L. (2012). Minimizing and treating chronicity in the eating disorders: a clinical overview. *International Journal of Eating Disorders,* Vol. 45(4): pp 467-475.

Appendix 1: Proof Reader Declaration



University of Central Lancashire

Declaration of Proof reading Services

Confirmatory Statement of Acceptance

Name of Candidate Laura Schut

Type of Award PhD

I declare that I have read, understood and have adhered to UCLan's Proofreading Policy (Appendix 1) when proof reading the above candidate's research degree thesis.

Signature of Proof reader: V. Hulse.

Print name: Vikki Hulse

Name of Company: Academic Proof-Reading Service

Contact Details:

Telephone: 07947 512223

Email: aprsvh@gmail.com

Appendix 2: STEMH Letter UCLAN

uclan
University of Central Lancashire

05 October 2017

Karen Wright / Laura Schut
School of Nursing
University of Central Lancashire

Dear Karen / Laura

Re: STEMH Ethics Committee Application
Unique Reference Number: **STEMH 801**

The STEMH ethics committee has granted approval of your proposal application 'An Exploration of the Perception of Life of Adult People, as influenced by the diagnosis of Severe and Enduring Anorexia Nervosa'. Approval is granted up to the end of project date*.

It is your responsibility to ensure that

- the project is carried out in line with the information provided in the forms you have submitted
- you regularly re-consider the ethical issues that may be raised in generating and analysing your data
- any proposed amendments/changes to the project are raised with, and approved, by Committee
- you notify roffice@uclan.ac.uk if the end date changes or the project does not start
- serious adverse events that occur from the project are reported to Committee
- a closure report is submitted to complete the ethics governance procedures (Existing paperwork can be used for this purposes e.g. funder's end of grant report; abstract for student award or NRES final report. If none of these are available use e-Ethics Closure Report Proforma).

Yours sincerely

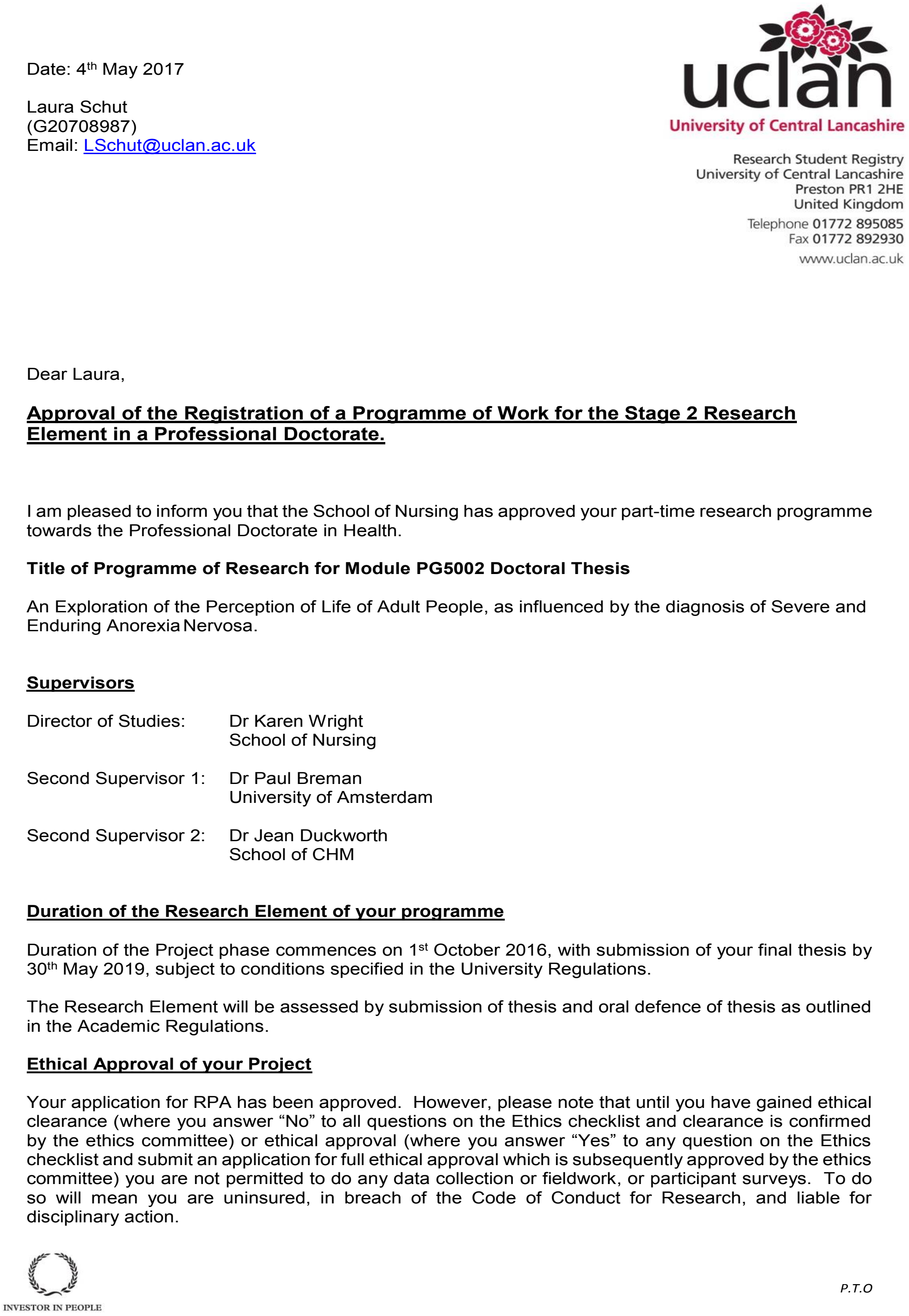
William Goodwin

William Goodwin
Deputy Vice Chair
STEMH Ethics Committee

* for research degree students this will be the final lapse date

NB - Ethical approval is contingent on any health and safety checklists having been completed, and necessary approvals as a result of gained.

Appendix 2.1: Approval of Registration Professional Doctorate - UCLAN



Date: 4th May 2017

Laura Schut
(G20708987)
Email: LSchut@uclan.ac.uk

Research Student Registry
University of Central Lancashire
Preston PR1 2HE
United Kingdom
Telephone 01772 895085
Fax 01772 892930
www.uclan.ac.uk

Dear Laura,

Approval of the Registration of a Programme of Work for the Stage 2 Research Element in a Professional Doctorate.

I am pleased to inform you that the School of Nursing has approved your part-time research programme towards the Professional Doctorate in Health.

Title of Programme of Research for Module PG5002 Doctoral Thesis

An Exploration of the Perception of Life of Adult People, as influenced by the diagnosis of Severe and Enduring Anorexia Nervosa.

Supervisors

Director of Studies:	Dr Karen Wright School of Nursing
Second Supervisor 1:	Dr Paul Breman University of Amsterdam
Second Supervisor 2:	Dr Jean Duckworth School of CHM

Duration of the Research Element of your programme

Duration of the Project phase commences on 1st October 2016, with submission of your final thesis by 30th May 2019, subject to conditions specified in the University Regulations.

The Research Element will be assessed by submission of thesis and oral defence of thesis as outlined in the Academic Regulations.

Ethical Approval of your Project

Your application for RPA has been approved. However, please note that until you have gained ethical clearance (where you answer "No" to all questions on the Ethics checklist and clearance is confirmed by the ethics committee) or ethical approval (where you answer "Yes" to any question on the Ethics checklist and submit an application for full ethical approval which is subsequently approved by the ethics committee) you are not permitted to do any data collection or fieldwork, or participant surveys. To do so will mean you are uninsured, in breach of the Code of Conduct for Research, and liable for disciplinary action.

P.T.O

Examination Arrangements

a) The arrangements for examining you on your programme of work.
b) The external and internal examiners to be appointed.

These arrangements should be submitted no later than 4 months before you propose to submit your thesis for examination. Please note that you will not be able to submit your thesis until examination arrangements have been approved.

Please feel free to contact me about any aspect of the registration procedures or with any other queries you may have.

Yours sincerely

pp.

Clare Wiggans
Senior Administrative Officer (Research)
Research Student Registry
Harris Building room HB103

Copies: Karen Wright
Paul Breman
Jean Duckworth
Victoria Hall-Moran

Appendix 3: METC Netherlands- Ask for Permission Letter (English version)

Discipline: Nursing
Supervisor: 1. Dr KM Wright PhD
2. Dr P Breman PhD
2. Dr JE Duckworth PhD
University of Central Lancashire
Researcher: Laura Schut
Date: December 2016
University ID Number G20708987
English translation of: The presentation letter for review by METC of Erasmus MC

Medical Ethical Examination Committee
Postbus 2040
3000 CA Rotterdam
Department of Administration
Chamber Ae-337

Date: 26-09-2016

Subject: Presentation of the research proposal for review of Medical-Scientific-Research obligation.

Dear Sir/Madam,

Hereby I forward you the research proposal for obligatory review of the Medical Ethics Committee, titled: An Exploration of the Perception of Life of Adult People, as influenced by the diagnosis of Severe and Enduring Anorexia Nervosa. "A *Grounded Theory research approach",*

I believe that this research is not within the scope of the Medical research Involving Human subjects Act (also known by its Dutch abbreviation WMO), due to the fact that the research involves:

- ○ Retrospective data are collected and processed (File research)
- ○ Prospective data are collected and processed
- ○ Tissue is used that is collected during normal diagnosis or care (residual tissue)
- ○ Administer of questionnaire(s) (see attached questionnaire)
- ○ Single collection of urine sample
- ✓ The research does not fit within the above categories, it includes the one-time conduct of an interview in persons with long-term eating disorder according to the methodology of the Grounded Theory

Signatories declare that:

1. By this research, the involved doctors, researchers and support staff are experienced and competent in research
2. All professionals should contribute in this research are enough informed about the project
3. The infrastructure in the Erasmus Medical Center or of the ward/department is suitable for a solid implementation of the investigation
4. There is no other research ongoing which draw attention and can complicate the success of this research
5. The number of participants that will be included in the Erasmus Medical Center, is attainable

If the research is supported by a profit-making enterprise, signatories declare to agree the METC-fee of € 600 for the assessment process by the METC Erasmus Medical Center.

If it is an external investigator-initiated research, whether or not supported by a profit-making enterprise, the signatories declare to agree to charge a METC-fee at the level of € 600 for the assessment process by the METC Erasmus Medical Center.

Discipline: Nursing
Supervisor: 1. Dr KM Wright PhD
2. Dr P Breman PhD
2. Dr JE Duckworth PhD
University of Central Lancashire
Researcher: Laura Schut
Date: December 2016
University ID Number G20708987
English translation of: The presentation letter for review by METC of Erasmus MC

The METC-fee is charged to:

Emergis, Mental Health Institution
Oostmolenweg 101
4481 PM Kloetinge
The Netherlands
Telephone: 0113 267000

Signatories declare to agree the submission of the named research proposal above at the METC.

Yours faithfully,

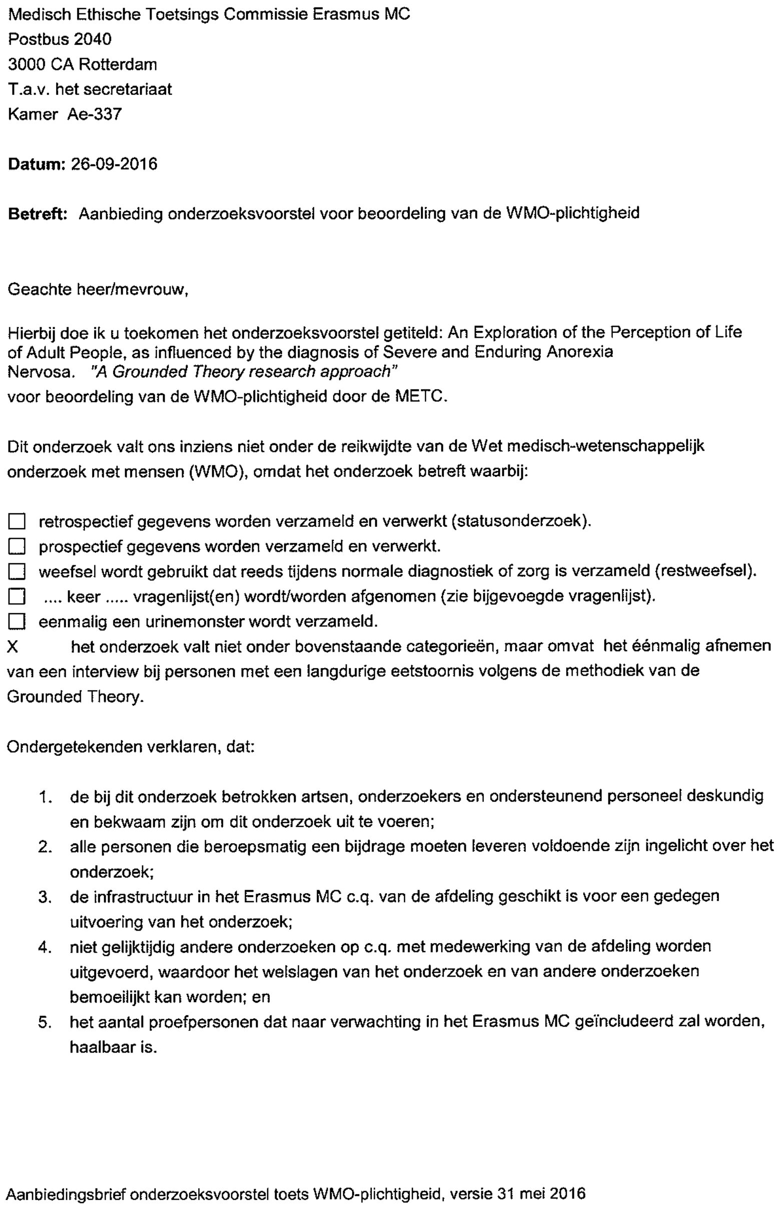
Name + signature	Name + signature
L Schut	
Master nurse specialist	Manager Department of research Emergis
Head researcher	Manager department

Addendum:

Research proposal

Sensitising concepts

Appendix 3.1: METC Netherlands- Ask for Permission Letter (Dutch original version)



Medisch Ethische Toetsings Commissie Erasmus MC
Postbus 2040
3000 CA Rotterdam
T.a.v. het secretariaat
Kamer Ae-337

Datum: 26-09-2016

Betreft: Aanbieding onderzoeksvoorstel voor beoordeling van de WMO-plichtigheid

Geachte heer/mevrouw,

Hierbij doe ik u toekomen het onderzoeksvoorstel getiteld: An Exploration of the Perception of Life of Adult People, as influenced by the diagnosis of Severe and Enduring Anorexia Nervosa. *"A Grounded Theory research approach"*
voor beoordeling van de WMO-plichtigheid door de METC.

Dit onderzoek valt ons inziens niet onder de reikwijdte van de Wet medisch-wetenschappelijk onderzoek met mensen (WMO), omdat het onderzoek betreft waarbij:

☐ retrospectief gegevens worden verzameld en verwerkt (statusonderzoek).
☐ prospectief gegevens worden verzameld en verwerkt.
☐ weefsel wordt gebruikt dat reeds tijdens normale diagnostiek of zorg is verzameld (restweefsel).
☐ .... keer ..... vragenlijst(en) wordt/worden afgenomen (zie bijgevoegde vragenlijst).
☐ eenmalig een urinemonster wordt verzameld.
X het onderzoek valt niet onder bovenstaande categorieën, maar omvat het éénmalig afnemen van een interview bij personen met een langdurige eetstoornis volgens de methodiek van de Grounded Theory.

Ondergetekenden verklaren, dat:

1. de bij dit onderzoek betrokken artsen, onderzoekers en ondersteunend personeel deskundig en bekwaam zijn om dit onderzoek uit te voeren;
2. alle personen die beroepsmatig een bijdrage moeten leveren voldoende zijn ingelicht over het onderzoek;
3. de infrastructuur in het Erasmus MC c.q. van de afdeling geschikt is voor een gedegen uitvoering van het onderzoek;
4. niet gelijktijdig andere onderzoeken op c.q. met medewerking van de afdeling worden uitgevoerd, waardoor het welslagen van het onderzoek en van andere onderzoeken bemoeilijkt kan worden; en
5. het aantal proefpersonen dat naar verwachting in het Erasmus MC geïncludeerd zal worden, haalbaar is.

Aanbiedingsbrief onderzoeksvoorstel toets WMO-plichtigheid, versie 31 mei 2016

Indien het onderzoek wordt ondersteund door een onderneming met winstoogmerk, verklaren ondergetekenden zich akkoord met het afboeken van een METC-fee ter hoogte van € 600 voor het beoordelingstraject door de METC Erasmus MC.

Indien het een extern investigator-initiated onderzoek betreft, al dan niet ondersteund door een onderneming met winstoogmerk, verklaren ondergetekenden zich akkoord met het in rekening te brengen van een METC-fee ter hoogte van € 600 voor het beoordelingstraject door de METC Erasmus MC.

De METC-fee komt ten laste van:

Kostenplaats:
Emergis, instelling Geestelijke Gezondheidszorg.
Oostmolenweg 101
4481PM
Kloetinge
Telefoon: 0113 267000

Ondergetekenden verklaren hiermee akkoord te gaan met de indiening van bovenvermeld onderzoeksvoorstel bij de METC.

Met vriendelijke groet,

Naam + handtekening	Naam + handtekening
L Schut	A Merks
Verpleegkundig specialist-GGZ	Manager kenniscentrum Emergis
Hoofdonderzoeker	Afdelingshoofd

(Verplicht in te vullen en te ondertekenen door beide partijen)

Bijlagen:

Onderzoeksvoorstel

Vragenlijst

Appendix 3.2: No Obligation Letter METC (English version)

L. Schut

Emergis, Mental Health Institution
Oostmolenweg 101
4481 PM Kloetinge

Subject: MEC-2016-715, Decision: Information of the Daily Board of the Medical Ethics Committee Erasmus MC (hereafter the Committee) of Rotterdam, the Netherlands. Rules laid down in the Medi Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO), do not apply this research proposal.

Protocol title: An Exploration of the Perception of Life of Adult People, as influenced by the diagnosi of Severe and Enduring Anorexia Nervosa. - "A *Grounded Theory research approach"*

Protocol version: 5, November 2016

Dear Sir/Mrs Schut,

On 22 November 2016, the Medical Ethics Committee Erasmus MC has received the above researc proposal submitted by you, in order to review the proposal for the rules laid down in the Medical Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO.

The daily board of the committee had decided that this proposal whether or not fits in the rules of th WMO. In conclusion of the daily board:

- The proposal includes a medical-scientific research question
- The participants are not submitted to an accomplishment or imposed to a certain behaviour as referred in the WMO

Because there is no compliance with either conditions for WMO obligatory, on 29th of November 201 the daily board of the committee had decided that the research as mentioned as above is not obligated for WMO. You may conduct your research in the Erasmus MC and, in due, you may offer your results for publication in a scientific journal.

The committee draw you attention to the following points:

- The committee only assessed the WMO obligatory, No further substantive examination has been conducted.

- You and your department are responsible for the correct conduct of the research, according the law- and guidelines. We draw your attention to the following points:

  - For prospective research, where there is a collection and analysis of personal data, requirement of participants is needed. You can find an example of a patient information-informed consent form for not-obligated research on the site of the METC (www.erasmusmc.nl/commissies/metc/)

  - For retrospective research, where data of participants will be coded, permission of the participants is needed. You can find an example of a patient information- informed consent form for not-obligated research on the site of the METC (www.erasmusmc.nl/commissies/metc/) (When conduct a retrospective *anonymous* research, permission is not obligated, data will be traceable)

  - When there is a data collection of participants in research, this needs to be handled carefully as described in the Behaviour Code Health Research (Code Good Behaviour), the Rules of Procedure of Privacy and the Act of Data Protection. You can find more information on the website of the METC (www.erasmusmc.nl/commissies/metc/) and on the website of FEDERA (www.federa.org)

  - When, in research, there is a collection of (body) tissues of participants, you to handle this correctly as provided in the Code Good Use. You can find more information on the website of FEDERA (www.federa.org)

  - The Board Committee for Population Research in accordance with the Act of Population Research must review obligatory licenced population research. You can find more information on the website of the CCMO (www.ccmo.nl)

  - Not WMO- obligated phase IV pharmaceutical research what is initiated by the pharmaceutical industry, must be attempt and conduct according the Behaviour –Code- Medicine – Advertisements. You can find more information on the website of the Foundation Code Medicines (www.cgr.nl)

  - Amendments and/or addenda within this research have to be assessed by the committee in order to decide if the research is still outside the scope of the WMO

- Researchers of the Erasmus MC have to comply to the research codes, as described in the edition “Research Codes” of the Department of Research Policy, you can find this report on the intranet

- For ethical screening of educational research refers the committee to the website of the NVMO-ERB (www.nvmo.nl)

The Committee invites you to inform her of the following data confirming the research:

- Start date (date inclusion first participant and/or start data collection
- End date (date stop research last participant) and/or stop data collection
- Publications and/or thesis

If you have any questions about the nature of methodological, financial, conduct of scientific research, you can consult the Consultation Center of Patient-related Research (CPO) for advise and help. The CPO organises multiple times a year the BROK course (basic course of regulations and organisation of clinical research), recommended by the committee. The BROK course is only obligated if research is WMO obligated. For information of the BROK data you can contact the congress bureau, internal telephone: 43584.

On the site of the METC you can find links of the above-mentioned law and guidelines. If you have any questions according this METC decision, you can contact the department of the METC.

According this research, this research will not be conducted in the Erasmus MC, researchers of the Erasmus MC are not involved, and however, this research must be proposed to the METC committee for screening. Therefore, a contribution towards the costs of the assessment process will be charged (METC-fee). The METC fee is € 600, -.

Yours faithfully,
In the name of the Medical Ethics Committee Erasmus MC,

Mw. Drs. N Loekabino

Secretary of the Committee

(Annex in English)

To whom it may concern,

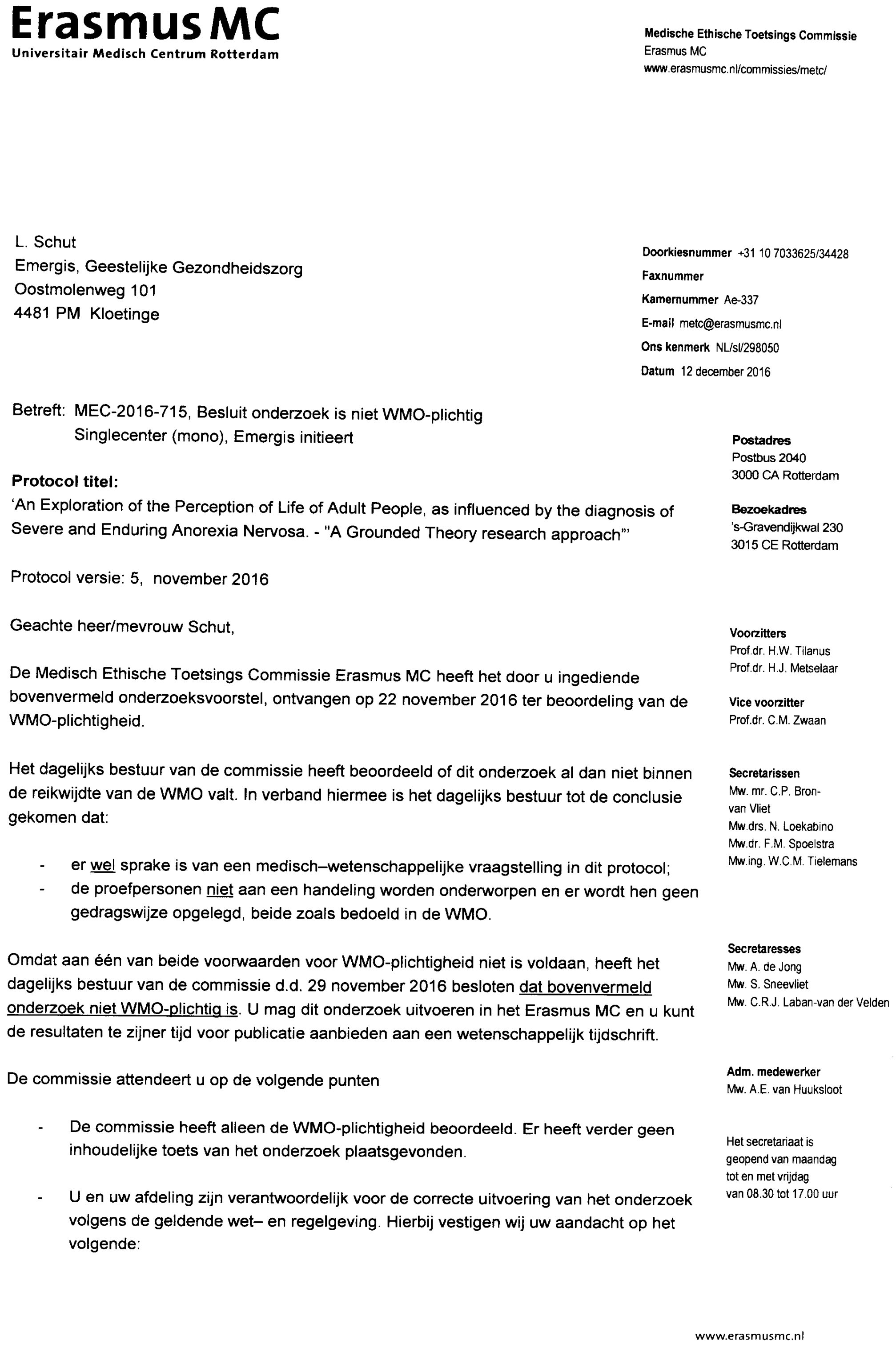
The Daily board of the Medical Ethics Committee Erasmus MC (hereafter the committee) of Rotterdam, The Netherlands, had reviewed the above mentioned research proposal. As a result of this review, the committee informs you that the rules laid down in the Medical research Involving Human subjects Act (also known by its Dutch abbreviation WMO) do not apply to this research proposal.

Yours faithfully,
In the name of the Medical Ethics Committee Erasmus MC,

Mw. Drs. N Loekabino

Secretary of the Committee
Please indicate the above MEC-number in every correspondence on this study.

Appendix 3.3: No Obligation Letter METC (Dutch version)



Erasmus MC
Universitair Medisch Centrum Rotterdam

Medische Ethische Toetsings Commissie
Erasmus MC
www.erasmusmc.nl/commissies/metc/

L. Schut
Emergis, Geestelijke Gezondheidszorg
Oostmolenweg 101
4481 PM Kloetinge

Doorkiesnummer +31 10 7033625/34428
Faxnummer
Kamernummer Ae-337
E-mail metc@erasmusmc.nl
Ons kenmerk NL/sl/298050
Datum 12 december 2016

Betreft: MEC-2016-715, Besluit onderzoek is niet WMO-plichtig
Singlecenter (mono), Emergis initieert

Protocol titel:
'An Exploration of the Perception of Life of Adult People, as influenced by the diagnosis of Severe and Enduring Anorexia Nervosa. - "A Grounded Theory research approach"'

Protocol versie: 5, november 2016

Geachte heer/mevrouw Schut,

De Medisch Ethische Toetsings Commissie Erasmus MC heeft het door u ingediende bovenvermeld onderzoeksvoorstel, ontvangen op 22 november 2016 ter beoordeling van de WMO-plichtigheid.

Het dagelijks bestuur van de commissie heeft beoordeeld of dit onderzoek al dan niet binnen de reikwijdte van de WMO valt. In verband hiermee is het dagelijks bestuur tot de conclusie gekomen dat:

- er wel sprake is van een medisch–wetenschappelijke vraagstelling in dit protocol;
- de proefpersonen niet aan een handeling worden onderworpen en er wordt hen geen gedragswijze opgelegd, beide zoals bedoeld in de WMO.

Omdat aan één van beide voorwaarden voor WMO-plichtigheid niet is voldaan, heeft het dagelijks bestuur van de commissie d.d. 29 november 2016 besloten dat bovenvermeld onderzoek niet WMO-plichtig is. U mag dit onderzoek uitvoeren in het Erasmus MC en u kunt de resultaten te zijner tijd voor publicatie aanbieden aan een wetenschappelijk tijdschrift.

De commissie attendeert u op de volgende punten

- De commissie heeft alleen de WMO-plichtigheid beoordeeld. Er heeft verder geen inhoudelijke toets van het onderzoek plaatsgevonden.
- U en uw afdeling zijn verantwoordelijk voor de correcte uitvoering van het onderzoek volgens de geldende wet– en regelgeving. Hierbij vestigen wij uw aandacht op het volgende:

Postadres
Postbus 2040
3000 CA Rotterdam

Bezoekadres
's-Gravendijkwal 230
3015 CE Rotterdam

Voorzitters
Prof.dr. H.W. Tilanus
Prof.dr. H.J. Metselaar

Vice voorzitter
Prof.dr. C.M. Zwaan

Secretarissen
Mw. mr. C.P. Bron-van Vliet
Mw.drs. N. Loekabino
Mw.dr. F.M. Spoelstra
Mw.ing. W.C.M. Tielemans

Secretaresses
Mw. A. de Jong
Mw. S. Sneevliet
Mw. C.R.J. Laban-van der Velden

Adm. medewerker
Mw. A.E. van Huuksloot

Het secretariaat is geopend van maandag tot en met vrijdag van 08.30 tot 17.00 uur

- Voor prospectief onderzoek, waarbij gegevens van proefpersonen worden verzameld en verwerkt, is toestemming van de proefpersonen nodig. U vindt een voorbeeld patiënteninformatie- en toestemmingsformulier voor niet WMO-plichtig onderzoek op de site van de METC. (www.erasmusmc.nl /commissies/metc/)

- Voor retrospectief onderzoek, waarbij gegevens van proefpersonen gecodeerd worden verzameld en verwerkt is toestemming van de proefpersonen nodig. U vindt een voorbeeld patiënteninformatie- en toestemmingsformulier voor niet WMO-plichtig onderzoek op de site van de METC (www.erasmusmc.nl /commissies/metc/).
  (Bij retrospectief *anoniem* onderzoek is toestemming niet verplicht, hierbij zijn de gegevens nooit meer herleidbaar tot de proefpersonen.)

- Wanneer in een onderzoek gegevens worden verzameld van proefpersonen, dient hiermee correct te worden omgegaan zoals bepaald in de Gedragscode Gezondheidsonderzoek (Code Goed Gedrag), het Privacy Reglement Erasmus MC, en de Wet bescherming persoonsgegevens.
  U vindt hierover meer informatie op de website van de METC (www.erasmusmc.nl /commissies/metc/) en op de website van FEDERA (www.federa.org).

- Wanneer in een onderzoek (lichaams)materiaal van proefpersonen wordt verzameld en verwerkt dient hiermee correct te worden omgegaan zoals bepaald in de Code Goed Gebruik. U vindt hierover meer informatie op de website van FEDERA (www.federa.org).

- Vergunningplichtig bevolkingsonderzoek moet worden ingediend bij de Commissie Bevolkingsonderzoek ter toetsing conform de Wet bevolkingsonderzoek. U vindt hierover meer informatie op de website van de CCMO (www.ccmo.nl).

- Niet WMO-plichtig Fase IV Geneesmiddelen onderzoek dat wordt geïnitieerd door de farmaceutische industrie dient te worden getoetst en uitgevoerd conform de Gedragscode Geneesmiddelenreclame. U vindt hierover meer informatie op de site van de stichting code geneesmiddelen reclame (www.cgr.nl).

- Amendementen en/of addenda bij dit onderzoek dienen aan de commissie ter beoordeling te worden voorgelegd zodat kan worden beoordeeld of het onderzoek nog steeds buiten de reikwijdte van de WMO blijft, of dat er door het amendement/addendum sprake is van WMO-plichtig onderzoek.

- Onderzoekers in het Erasmus MC dienen zich te houden aan de research codes, zoals vastgelegd in de uitgave 'Research Codes' van de afdeling Onderzoeksbeleid, te vinden op Intranet.

- Voor ethische toetsing van Onderwijsonderzoek verwijst de commissie u naar de website van de NVMO-ERB (www.nvmo.nl).

- De commissie verzoekt u haar op de hoogte te brengen van de volgende gegevens betreffende dit onderzoek:
    - Startdatum (datum inclusie eerste proefpersoon) en/of start gegevens onderzoek
    - einddatum (datum stop studie laatste proefpersoon) en/of stop gegevens onderzoek
    - publicaties en/of eindrapport

Wanneer u vragen heeft over het opzetten, financieren, of uitvoeren van wetenschappelijk onderzoek, kunt u terecht bij het Consultatiecentrum Patiëntgebonden Onderzoek (CPO) voor advies en hulp. Het CPO organiseert ook meerdere keren per jaar de BROK cursus (Basiscursus Regelgeving en Organisatie van Klinisch Onderzoek), die door de commissie van harte wordt aanbevolen. Het volgen van de BROK cursus is, conform landelijke afspraken, alleen verplicht bij WMO-plichtig onderzoek. Voor informatie over de BROK-cursusdata kunt u contact opnemen met het Congresbureau, intern tel.nr. 43584.

Op de site van de METC kunt u links terugvinden naar de hierboven vermelde wet- en regelgeving. Wanneer u vragen heeft over dit METC besluit, kunt u contact opnemen met het secretariaat van de METC.

Het betreft een onderzoek dat niet in of met medewerking van onderzoekers van het Erasmus MC wordt uitgevoerd, maar dat wel aan de METC Erasmus MC ter beoordeling wordt voorgelegd. Er wordt een tegemoetkoming in de kosten van het beoordelingstraject (METC-fee) in rekening gebracht. De METC-fee hiervoor bedraagt € 600.

Met vriendelijke groet,
namens de Medisch Ethische Toetsings Commissie Erasmus MC,

i.o.

Mw.drs. N. Loekabino
Secretaris

To whom it may concern,

The Daily Board of the Medical Ethics Committee Erasmus MC (hereafter the Committee) of Rotterdam, The Netherlands, has reviewed the above mentioned research proposal. As a result of this review, the Committee informs you that the rules laid down in the Medical Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO), do not apply to this research proposal.

Please indicate the above MEC-number in every correspondence on this study

Yours sincerely,
On behalf of the Medical Ethics Committee Erasmus MC,

i.o.

Mrs. N.Loekabino, MSc
Secretary of the Committee

Cc. **Digitale verzending**
A. Merks

Appendix 4: Information Letter (English version)

Emergis
uclan
University of Central Lancashire

Information sheet - Letter of invitation to participants

Name of the study: *An Exploration of the Quality of Life of Persons Living with a diagnosis of Severe and Enduring Anorexia Nervosa in Adulthood using a Grounded Theory approach.*

Dear Madam, Sir,
You have been invited to participate in a scientific research. Before you decide to participate in this research, it is important to understand why and how this research is done.
In this letter, you can read all the information about this research and please take your time to read the information carefully. If you wish, discuss the decision, whether or not to join, in this research with your family and friends. Please take the time to decide whether or not you wish to participate.

What is the purpose of this research?
The purpose of this research is that little is known about people with severe and enduring anorexia nervosa. Current treatment is developed for people with an acute form of anorexia nervosa. Therapists know that this treatment does not have the positive effects for people with severe and enduring anorexia nervosa. Also, there is knowledge that people with severe and enduring anorexia want to improve their health or quality of life.

Therapists use the guidelines in the treatment of eating disorders. Current treatment involves weight gain and the improvement of the menu. For a lot of patients, both items are very helpful, however, some people do not benefit of it. In this study, there is a search for what kind of treatment question has the people with severe and enduring anorexia nervosa.

The method of this study is performing interviews with informants. Informants are: people with severe and enduring anorexia, family and/or friend of people with severe and enduring anorexia, expert therapists. The interviews will carefully analyzed, sometimes, if important data is missing, a new interview can be performed. At the end, gain data will be compared with findings in the literature; at last, results of the research will be written down in a theory.

How does this research work for the participant?
In the study, you take part of a personal interview with the researcher. The researcher will attempt to meet you if necessary. The interviews will be recorded on a voice recorder. The interviews will be 60

minutes long. Before you take part of the interview, you have to sign an informed consent and you declare verbally, that you will participate in the interview.

What are the possible risks?

This research will do you no physical harm but it is possible that you get mentally confused because of the questions. For this reason, the researcher regulates psychological support, if needed; the researcher will contact a professional trained psychologist in eating disorders to offer you psychological help. Further on, if there are complaints about the way in which the study has been conducted, please contact the research office of the UCLAN by using this link: OfficerforEthics@uclan.ac.uk

Because of the vulnerability of people with severe and enduring anorexia nervosa, the people will be asked if they prefer to have contact by telephone, or computer, using Skype or Face Time, or in real life, by performing a face-to-face conversation.

What are the benefits?

If you perform in this research, the will be no direct benefits. However, in the future, your participation can benefit the people with severe and enduring anorexia nervosa, because knowledge of the phenomenon can lead to a better treatment.

What if you decide not to join the research?

Nothing will happen if you decide not to join the research, it will not effect any subsequent treatment.

How about the privacy?

There are a few people involved in this research; the researcher, the supervisor of the researcher and the superintendent of the hospital (Emergis, the Netherlands). All these people do have access to confidential papers. To protect your private data, all this people sign for confidentiality. Results of the study will be made anonymous. Your name will not be published.

Can I have aments?

As a participant you are considered for ament if you make travelling costs.

How about other rights?

You have the right to have all the information about the research, so you can make a good decision whether you want to participate the study or not. You will have the right to think about you decision to participate for three weeks. Only you decide if you participate, if you do, you will have to sign an informed consent. If you decide to participate, you can stop at any time, without explaining why. The researcher can decide to stop the research if there are medical reasons.

What if I have questions or complaints?

If you have any questions, do not hesitate to ask to the researcher, Laura Schut. If you have any complaints about the research, please feel free to speak about it with the researcher.
You can contact the researcher: Laura Schut, master nurse specialist, department: eating disorders of Emergis, Abbekindersezandweg 2, Kloetinge. Phone number: (31) 0113267766.
moerland@emergis.nl

Appendix 4.1: Information Letter (Dutch version)

Informatiebrief- Uitnodiging voor participatie in wetenschappelijk onderzoek

Naam van de studie: *An Exploration of the Quality of Life of Persons Living with a diagnosis of Severe and Enduring Anorexia Nervosa in Adulthood using a Grounded Theory approach.*

Geachte mevrouw, meneer,
U bent uitgenodigd om mee te doen in een wetenschappelijk onderzoek. Voordat u beslist hieraan meet e doen, is het belangrijk dat u geheel begrijpt waarom en hoe dit onderzoek wordt gedaan.
In deze brief kunt u alle informatie vinden over dit onderzoek en leest u de brief daarom goed door.
Als u behoefte heeft de beslissing te bespreken, om al dan niet mee te doen met dit onderzoek, bespreekt u deze informatie dan gerust met uw familie en /of vrienden. Neemt u gerust de tijd om de beslissing te nemen.

Wat is het doel van dit onderzoek?
Het doel van dit onderzoek is meer wetenschappelijke kennis te ontwikkelen over personen met langdurige anorexia nervosa. De huidige behandeling is ontwikkeld voor mensen met een acute vorm van anorexia nervosa. Behandelaren zijn op de hoogte dat de huidige vorm van behandeling weinig positieve effecten heeft in de behandeling van personen met langdurige anorexia nervosa. Inmiddels is e rook een wetenschappelijke overtuiging dat patiënten met langdurige anorexia nervosa zich willen richten op de verbetering van de kwaliteit van leven.

Behandelaren maken gebruik van de richtlijnen in de behandeling van Eetstoornissen. De huidige behandeling betreft het verbeteren van het gewicht en verbetering van het eetpatroon. Voor veel mensen is dit ook zeer waardevol, maar helaas profiteert niet iedere eetstoornispatiënt hiervan. In deze studie wordt gezocht naar de behandelvraag of professionele ondersteuning die patiënten met een langdurige eetstoornis hebben.

De methode van deze studie is de volgende: Informatie wordt vergaard door middel van interviews met personen, participanten genoemd. De participanten kunnen zijn: personen met een ernstige en langdurige anorexia nervosa, familie en/of vrienden van personen met langdurige anorexia nervosa. En expert therapeuten. De interviews worden stap voor stap geanalyseerd, mochten er belangrijke gegevens gemist worden, dan wordt er opnieuw een interview uitgevoerd. Aan het eind van het onderzoek zullen alle verzamelde gegevens met elkaar worden vergeleken met bevindingen in wetenschappelijke artikelen, uiteindelijk wordt een theorie beschreven in een eindproduct, een thesis.

Wat betekent dit voor u als deelnemer?
In deze studie, neemt u deel aan een persoonlijk interview met de onderzoeker. Het interview wordt digital opgenomen en duren maximaal 60 minuten. Voordat u deelneemt aan het interview, tekent u een formulier (informed consent) en verklaart u mondeling dat u vrijwillig meedoet met het onderzoek.

Zijn er eventuele risico's?
In dit onderzoek zal u geen fysieke schade oplopen. Wel is het mogelijk dat u psychisch verward kan worden vanwege de vragen die u worden gesteld. Vanwege dit feit kan de onderzoeker u psychische ondersteuning aanbieden als u dat wenst. De onderzoeker zal contact leggen met een hulpverlener, gespecialiseerd in eetstoornissen en voor u desgewenst een afspraak in laten plannen.

Vanwege de kwetsbaarheid van mensen met een ernstige eetstoornis, zal aan u worden gevraagd of u het interview via telefoon, Skype, of face time, of Face to face wilt.

Wat zijn de voordelen?
Er zijn geen directe voordelen verbonden aan het meedoen aan dit onderzoek. Toch, in de toekomst kan uw bijdrage zeer waardevol zijn in de behandeling van mensen met langdurige anorexia nervosa. Deze kennis kan een bijdrage leveren aan een betere behandeling.

Wat gebeurt er als u niet meedoet met dit onderzoek?
Als u besluit niet mee te doen aan dit onderzoek, dan heeft dat geen enkele gevolg voor u en uw eventuele behandeling.

Hoe zit het met uw privacy?
Er zijn enkele mensen betrokken bij dit onderzoek; De onderzoeker zelf, de supervisors van de onderzoeker en de Raad van Bestuur van Emergis. Al deze mensen hebben toegang tot vertrouwelijke documenten. Om uw persoonlijke gegevens (data) te beschermen, zullen deze mensen moeten tekenen om deze data in te zien. Daarnaast worden resultaten van de studie anoniem gemaakt, uw naam zal niet worden gepubliceerd.

Krijgt u een vergoeding?

Als deelnemer heeft u recht op een vergoeding als u reiskosten heeft gemaakt.

Hoe zit het met andere rechten?

U heeft het recht op alle informatie over het onderzoek zodat een goede beslissing kan maken of u wel of niet mee wilt doen. U heeft het recht drie weken over uw beslissing na te denken. Alleen u bepaalt of u mee wilt doen, echter, als u besluit meet e doen, dan tekent u een *informed consent.* Ook als u besluit meet e doen, dan kunt u ten alle tijde stoppen. U bent niet verplicht uitleg te geven over uw beslissing. De onderzoeker kan besluiten uw deelname te stoppen vanwege medische redenen.

Wat als u vragen of klachten heeft?

Als u vragen heeft, aarzel niet deze te stellen aan de onderzoeker, Laura Schut. Als u klachten heeft over de gang van zaken van het onderzoek, geeft u dit alstublieft aan bij de onderzoeker.

U kan de onderzoeker op volgende wijze contacten: Laura Schut, master nurse specialist, Zorgprogramma : Eetstoornissen Emergis, Abbekindersezandweg 2, Kloetinge. Telefoonnummer : (31) 0113267766. moerland@emergis.nl

Appendix 5: Informed Consent Form (English Version)

Emergis

uclan
University of Central Lancashire

Consent form

Name of the study: *An Exploration of the Quality of Life of Persons Living with a diagnosis of Severe and Enduring Anorexia Nervosa in Adulthood using a Grounded Theory approach.*

Method: interview
Researcher: Laura Schut

By signing this consent, I declare that I understand the information below:

Yes / No

☐ ☐ I am well informed and I understand the information sheet dated on …………… for the above study

☐ ☐ I have had the opportunity to ask questions about the research to the researcher

☐ ☐ I have understand that I will be informed by the researcher if there's will be any important information, connected to the previous named study, available

☐ ☐ I give permission to record the interview

☐ ☐ I give permission to store my personal data and I am aware that my personal data will be made anonymous and my personal data will not be named in any final report

☐ ☐ My information will be addressed according to the law of the protection of personal data

☐ ☐ I participation in this research is completely voluntary and I am, at any time, free withdraw in further participation of this research, this will not effect any subsequent treatment

☐ ☐ I do have the right to ask for any psychological help if needed

Name/signature participant:

Name/signature researcher:

Date:

Date:

Appendix 5.1: Informed Consent Form (Dutch Version)

Emergis uclan University of Central Lancashire

Consent form

Naam studie: *An Exploration of the Perception of Life of Adult People, as influenced by the diagnosis of Severe and Enduring Anorexia Nervosa. A Grounded Theory Approach.*

Methode: interview
Onderzoeker: Laura Schut

Bij ondertekening van deze overeenkomst, verklaar ik dat ik akkoord ben en het onderstaande heb begrepen:

Ja	Nee	
☐	☐	Ik ben goed geïnformeerd over de studie en ik begrijp de informatie brief, gedateerd op……van bovenstaande studie.
☐	☐	Ik heb de kans gekregen om vragen te stellen aan de onderzoeker.
☐	☐	Ik heb begrepen dat ik word geïnformeerd door de onderzoeker indien er sprake is van relevante informatie welke in verband staat met bovenstaande studie.
☐	☐	Ik geef toestemming het interview op te nemen op een geluidsdrager.
☐	☐	Ik geef toestemming mijn persoonlijke date op te slaan en ik ben mij ervan bewust dat mijn persoonlijke data zal worden geanonimiseerd en mijn naam zal niet worden genoemd in het een eindrapport.
☐	☐	Mijn persoonlijke informatie zal worden behandeld volgens de wet op de dataprotectie.
☐	☐	Mijn deelname in dit onderzoek is volledig vrijwillig en ik kan, zonder opgaaf van redenen, op ieder gewenst tijdstip stoppen met deze deelname, dit heft geen effect op een eventuele behandeling
☐	☐	Ik heb het recht op het vragen van psychologische hulp of ondersteuning als ik dat nodig vind.

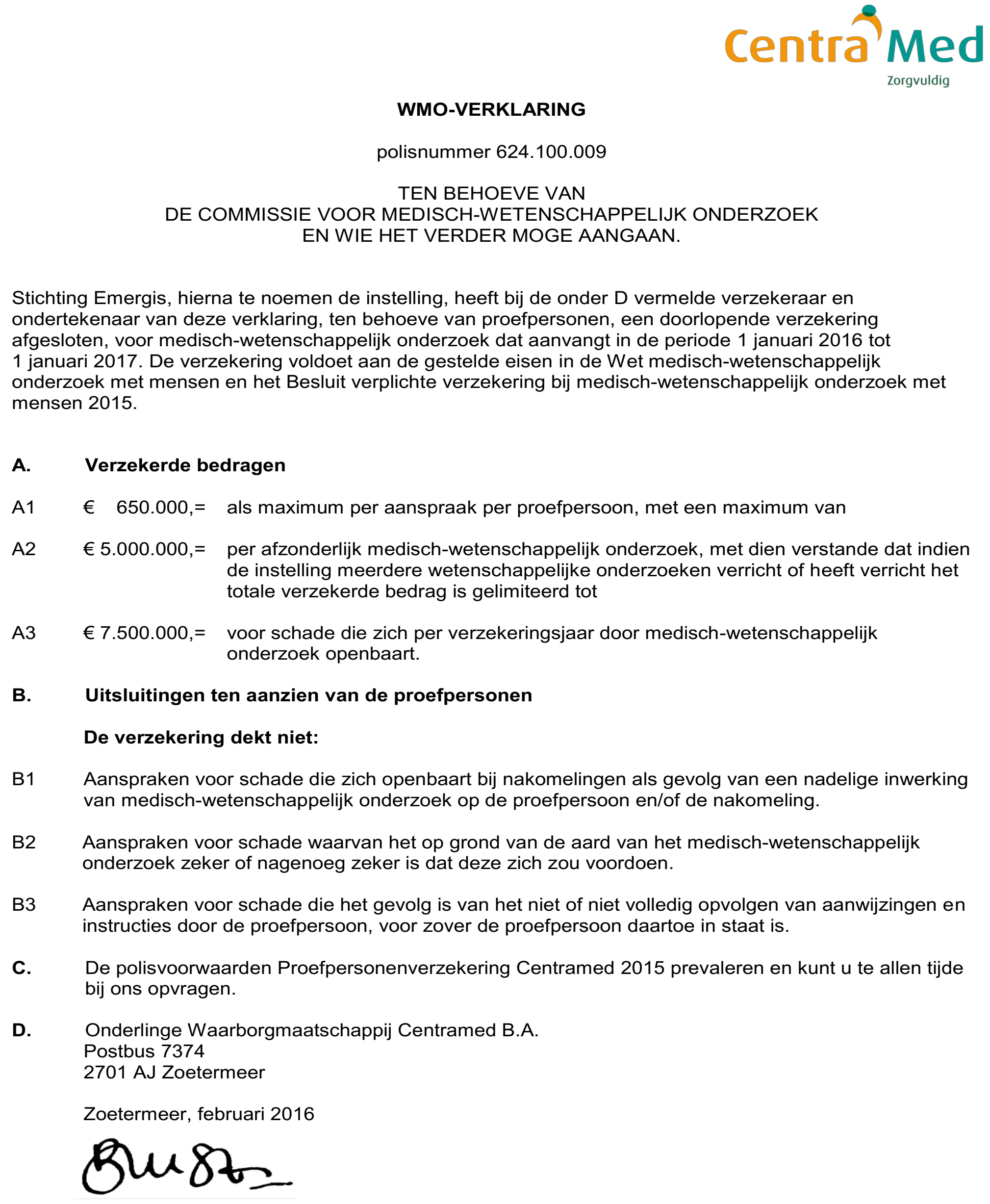
Naam/ handtekening participant:

Naam / handtekening onderzoeker:

Datum:

Datum:

Appendix 6: Declaration of Patient Insurance



CentraMed
Zorgvuldig

WMO-VERKLARING

polisnummer 624.100.009

TEN BEHOEVE VAN
DE COMMISSIE VOOR MEDISCH-WETENSCHAPPELIJK ONDERZOEK
EN WIE HET VERDER MOGE AANGAAN.

Stichting Emergis, hierna te noemen de instelling, heeft bij de onder D vermelde verzekeraar en ondertekenaar van deze verklaring, ten behoeve van proefpersonen, een doorlopende verzekering afgesloten, voor medisch-wetenschappelijk onderzoek dat aanvangt in de periode 1 januari 2016 tot 1 januari 2017. De verzekering voldoet aan de gestelde eisen in de Wet medisch-wetenschappelijk onderzoek met mensen en het Besluit verplichte verzekering bij medisch-wetenschappelijk onderzoek met mensen 2015.

A. **Verzekerde bedragen**

A1	€ 650.000,=	als maximum per aanspraak per proefpersoon, met een maximum van
A2	€ 5.000.000,=	per afzonderlijk medisch-wetenschappelijk onderzoek, met dien verstande dat indien de instelling meerdere wetenschappelijke onderzoeken verricht of heeft verricht het totale verzekerde bedrag is gelimiteerd tot
A3	€ 7.500.000,=	voor schade die zich per verzekeringsjaar door medisch-wetenschappelijk onderzoek openbaart.

B. **Uitsluitingen ten aanzien van de proefpersonen**

De verzekering dekt niet:

B1 Aanspraken voor schade die zich openbaart bij nakomelingen als gevolg van een nadelige inwerking van medisch-wetenschappelijk onderzoek op de proefpersoon en/of de nakomeling.

B2 Aanspraken voor schade waarvan het op grond van de aard van het medisch-wetenschappelijk onderzoek zeker of nagenoeg zeker is dat deze zich zou voordoen.

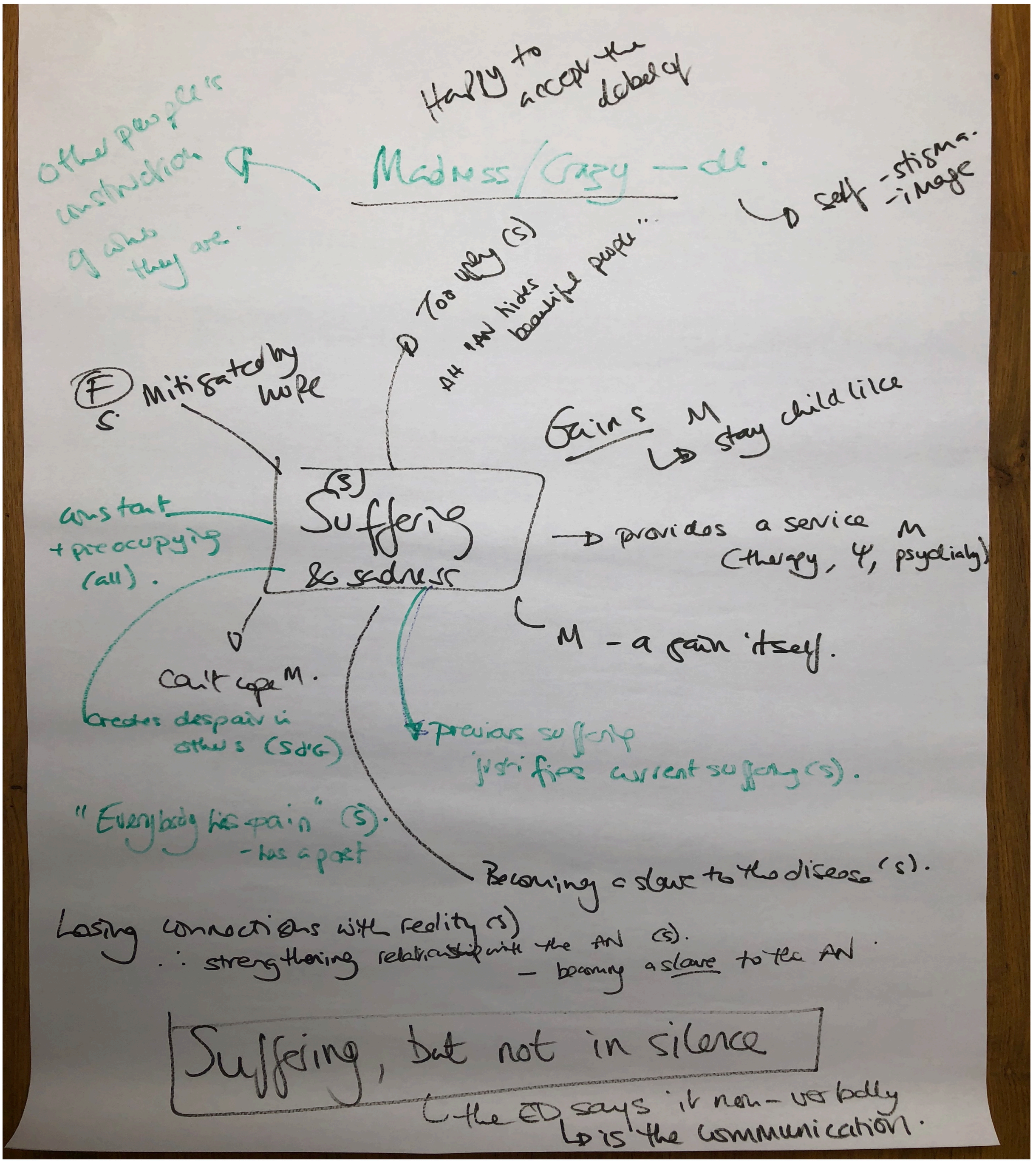
B3 Aanspraken voor schade die het gevolg is van het niet of niet volledig opvolgen van aanwijzingen en instructies door de proefpersoon, voor zover de proefpersoon daartoe in staat is.

C. De polisvoorwaarden Proefpersonenverzekering Centramed 2015 prevaleren en kunt u te allen tijde bij ons opvragen.

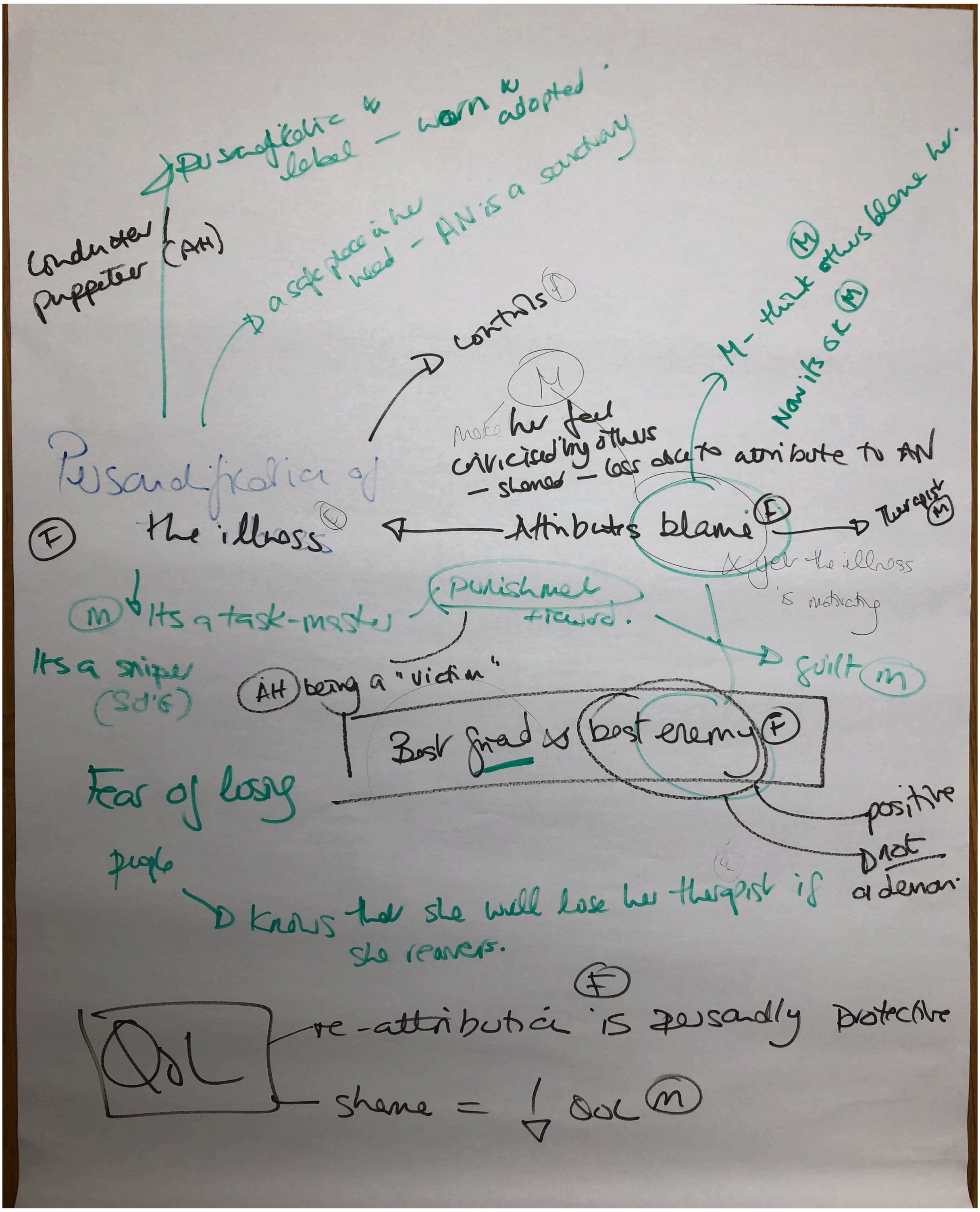
D. Onderlinge Waarborgmaatschappij Centramed B.A.
Postbus 7374
2701 AJ Zoetermeer

Zoetermeer, februari 2016

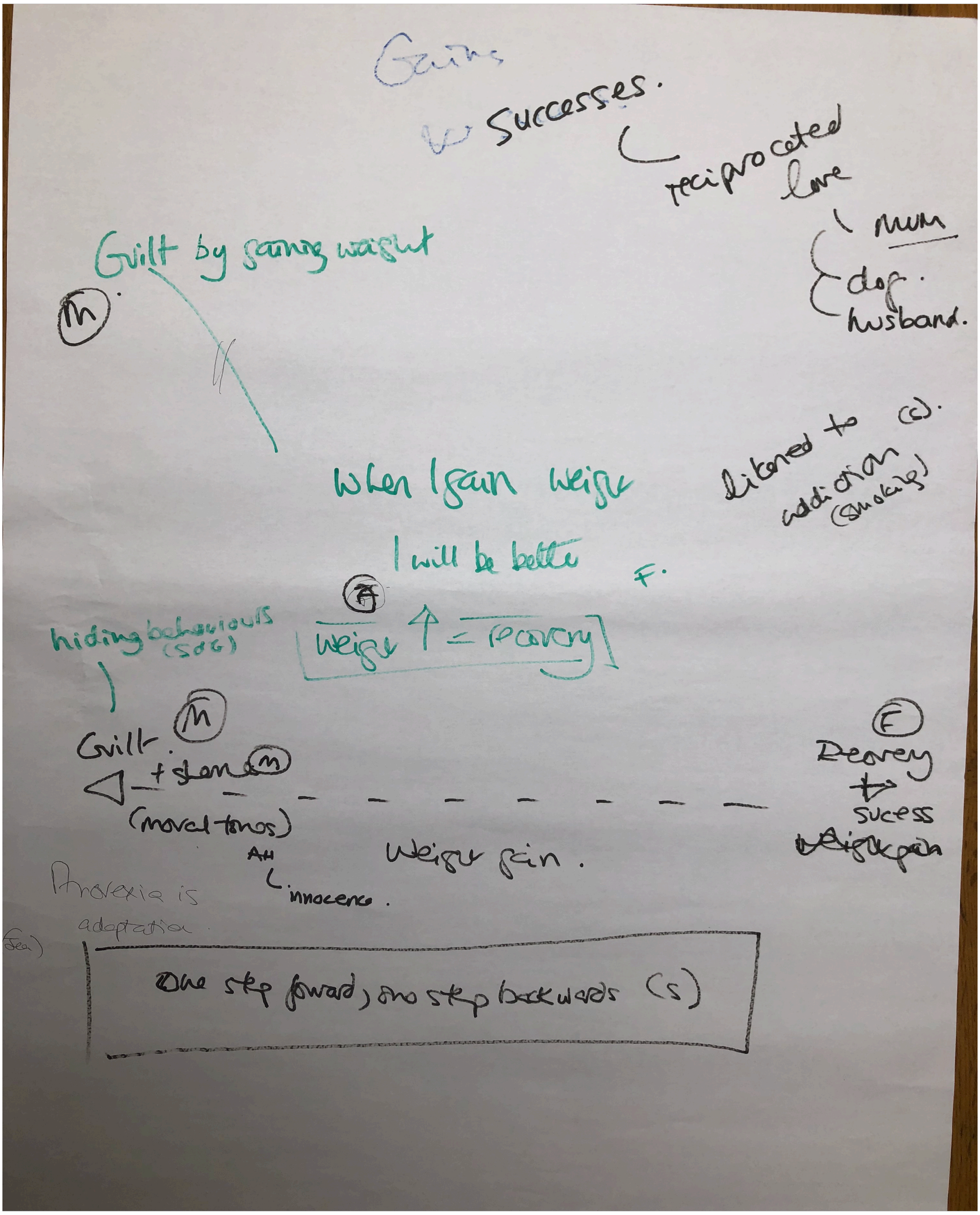
Appendix 7: Original Messy Mind Map, ‘Suffering, but not in Silence’



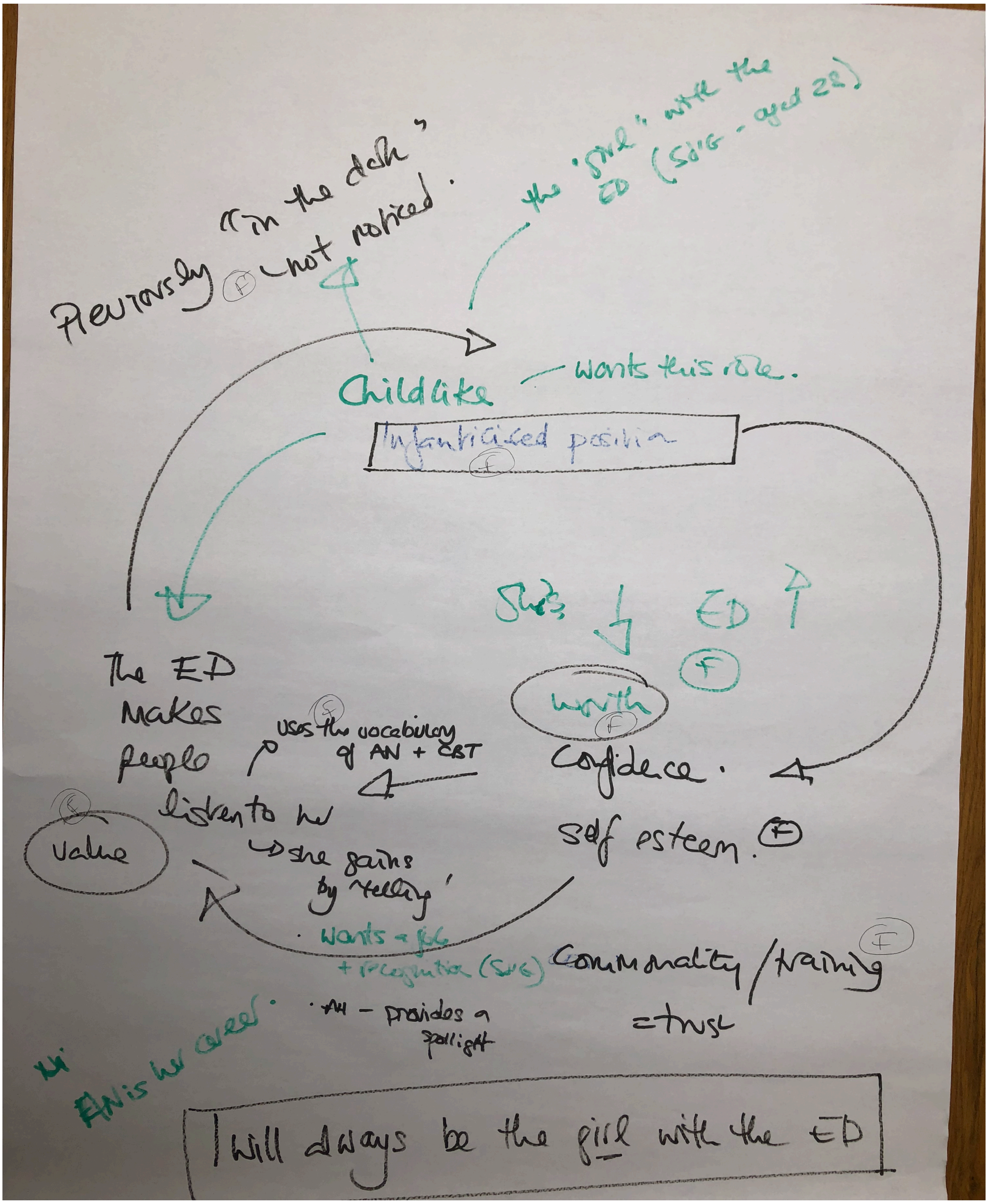
Appendix 7.1: Original Messy Mind Map, ‘Best Friend, Best Enemy’



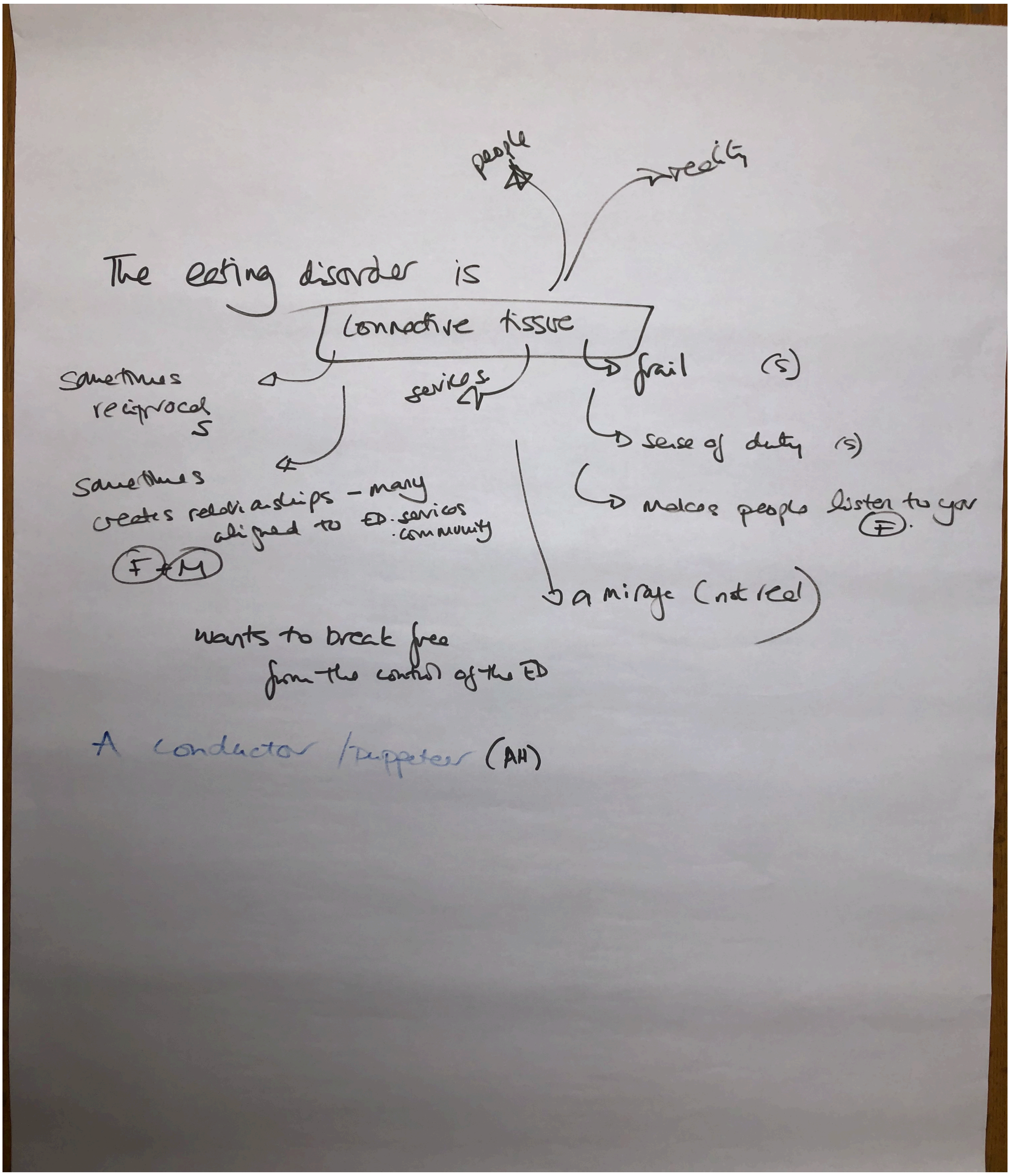
Appendix 7.2: Original Messy Mind Map, ‘One step forward, one step backwards’



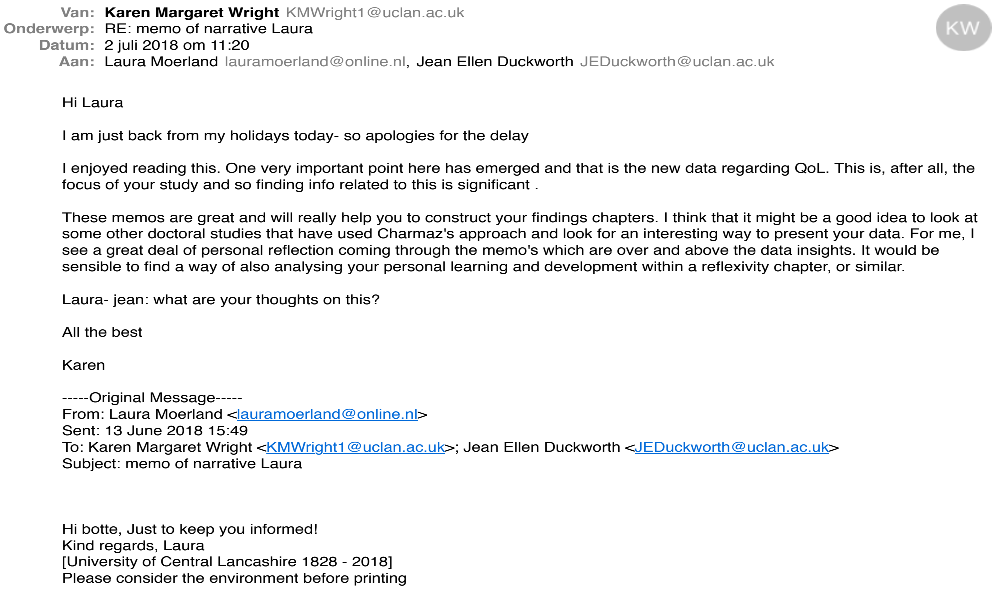
Appendix 7.3: Original Messy Mind Map, ‘I will always be the girl with the eating disorder’



Appendix 7.4: Original Messy Mind map, ‘Connective tissue’



Appendix 8: Example of E-mail Correspondence with the Supervisory Team of UCLAN



Van: **Karen Margaret Wright** KMWright1@uclan.ac.uk
Onderwerp: RE: memo of narrative Laura
Datum: 2 juli 2018 om 11:20
Aan: Laura Moerland lauramoerland@online.nl, Jean Ellen Duckworth JEDuckworth@uclan.ac.uk

Hi Laura

I am just back from my holidays today- so apologies for the delay

I enjoyed reading this. One very important point here has emerged and that is the new data regarding QoL. This is, after all, the focus of your study and so finding info related to this is significant .

These memos are great and will really help you to construct your findings chapters. I think that it might be a good idea to look at some other doctoral studies that have used Charmaz's approach and look for an interesting way to present your data. For me, I see a great deal of personal reflection coming through the memo's which are over and above the data insights. It would be sensible to find a way of also analysing your personal learning and development within a reflexivity chapter, or similar.

Laura- jean: what are your thoughts on this?

All the best

Karen

-----Original Message-----
From: Laura Moerland <lauramoerland@online.nl>
Sent: 13 June 2018 15:49
To: Karen Margaret Wright <KMWright1@uclan.ac.uk>; Jean Ellen Duckworth <JEDuckworth@uclan.ac.uk>
Subject: memo of narrative Laura

Hi botte, Just to keep you informed!
Kind regards, Laura
[University of Central Lancashire 1828 - 2018]
Please consider the environment before printing

Appendix 9: Coding Matrix: ‘Suffering, but not in Silence’

Coding families	Concepts	Examples
The Six C’s	Causes, contexts, contingencies, consequences, conditions	Of suffering: losing contacts, defining attention through the suffering, declined psychological functioning, declined physical functioning, loneliness
Process	Stages, phases, phasing’s, transitions, passages, careers, chains, sequences	Several stages of suffering, on-going construct of suffering, different dimensions of suffering
Degree Family	Extent, level, intensity, range, amount, continuum, statistical average, standard deviation	
Type Family	Types, classes, genres, prototypes, styles, kinds	Types of suffering: physical pain, psychological burden, loneliness, experiencing negative emotions, feelings of loss
Strategy Family	Strategies, tactics, techniques, mechanism, management	Interaction with suffering, coping style: staying childlike, avoiding social contacts, contacts are made by continuous suffering, suffering provides contact within the services
Interactive Family	Interaction, mutual effects, interdependence, reciprocity, symmetries, rituals	Interdependency with suffering, suffering as a gain itself, maintaining contacts with healthcare workers, suffering is the communication
Identity-Self Family	Identity, self-image, self concept self-evaluation, social worth, transformations of self	Childish identity, dependent behaviours, loss of identity and lacks matureness
Cutting-point Family	Boundary, critical juncture, cutting point, turning point, point of no return	Starting point for a medical career as a Patient, suffering is a legal way to be seen as a patient
Cultural Family	Social norms, social values, social beliefs	Social norms according to tolerating suffering and non tolerating suffering as seen through the constructs of others, defining stigma
Consensus Family	Contracts, agreements, definitions of the situation, uniformity, conformity, conflict	Compliance: acceptance of the AN status according to suffering, adaption of the AN condition, suffering and AN are bread and butter

Appendix 9.1: Coding Matrix: 'One step forward, One step backwards'

Coding families	Concepts	Examples
The Six C's	Causes, contexts, contingencies, consequences, conditions	Causes of weight gain: in-patient treatment whereby focus on weight gain only, appointments with healthcare workers, internal motivation to gain weight, lack of motivation to gain weight
Process	Stages, phases, phasing's, transitions, passages, careers, chains, sequences	Career of a patient with a chronic eating disorder condition, losing weight versus gaining weight (in therapies, the use of duress in the past
Degree Family	Extent, level, intensity, range, amount continuum, statistical average, standard deviation	In previous treatment focus on weight gain.
Type Family	Types, classes, genres, prototypes, styles, kinds	
Strategy Family	Strategies, tactics, techniques, mechanism, management	Stabilizing weight (mostly low) supports hidden Behaviours (hidden for family, therapists, relatives).
Interactive Family	Interaction, mutual effects, interdependence, reciprocity, symmetries, rituals	Interactions with weight gain, using a coping style of guilt and shame to deal with the phenomenon. Hidden behaviours are mostly in charge to hide weight loss. Weight gain is reciprocating love, attention and care from relatives, family, social world. Weight gain stands for success and recovery, constructs of others: 'the patient will be better', rituals in weigh
Identity-Self Family	Identity, self-image, self concept, self-evaluation, social worth, transformations of self	Identity of remaining innocent when ill, being thin is remain innocent, stay 'childlike'. Gaining weight is 'mature' what refers to having adult responsibilities, Self –concept experiencing 'guilt and shame'.
Cutting-point Family	Boundary, critical juncture, cutting point, turning point, point of no return	Indicates a medical career as a patient resulting in a cyclic process referring to weight gain versus weight loss
Cultural Family	Social norms, social values, social beliefs	Social norms: non-toleration of maintaining low weight, refusal to recover, lack of understanding feelings of shame and guilt in the context of SE-AN in social world, stigma, loss of contacts, keeping distances
Consensus Family	Contracts, agreements, definitions of the situation, uniformity, conformity, conflict	Compliance in the cyclic process, adaption of the AN

Appendix 9.2: Coding Matrix: 'Connective Tissue'

Coding families	Concepts	Examples
The Six C's	Causes, contexts, contingencies, consequences, conditions	Of connective tissue: context: contacts within ED patients, within relatives, family, therapists, services
Process	Stages, phases, phasing's, transitions, passages, careers, chains, sequences	Several stages; non-verbally (see me ill, appearance of the participant), part non-verbally, part verbally; communication through the child-like attitude, keep away of communication by maintaining distance. Transition is possible, AN builds longstanding relationships
Degree Family	Extent, level, intensity, range, amount, continuum, statistical average, standard deviation	Intensity: Building friendships with peer group members, take distance of peer group members. Stay in contact with family/relatives/ keep distance of family/relatives of breaks relationships
Type Family	Types, classes, genres, prototypes, styles, kinds	Types: communication, non-verbally communication through behaviours, appearance of SE-AN participants, using social media, building on a 'dream world'
Strategy Family	Strategies, tactics, techniques, mechanism, management	Strategy: 1: The AN as a strategy in contacts with others, because of 'living in a mirage' and losing contact with reality and the on-going vulnerability and being ill: With this, distance is created but gives access to services Participants become unapproachable for outsiders 2: The ED creates relationships, friendships and contacts (mostly with other ED patients), sharing the same experiences, "we all in this together"
Interactive Family	Interaction, mutual effects, interdependence, reciprocity, symmetries, rituals	AN creates interdependency with itself, self fulfilling prophecy whereby clear unbreakable patterns in communication. SE-AN participants judge themselves negatively
Identity-Self Family	Identity, self-image, self concept self-evaluation, social worth, transformations of self	AN becomes the way to connect with people, AN has the lead, which can lead to self fulfilling prophecy and the loss of self esteem
Cutting-point Family	Boundary, critical juncture, cutting point, turning point, point of no return	AN in the function of connective tissue indicates an enduring situation
Cultural Family	Social norms, social values, social beliefs	Social norms: non-acceptance of the SE-AN status, leads to stigma
Consensus Family	Contracts, agreements, definitions of the situation, uniformity, conformity, conflict	Compliance: acceptance of the SE-AN condition, indicates adaption, patients 'belong to a group', experience similarity and conformity, they are frail and live in a mirage

Appendix 9.3: Coding Matrix: 'Best Friend, Best Enemy'

Coding families	Concepts	Examples
The Six C's	Causes, contexts, contingencies, consequences, conditions	Of the theoretical finding best friend, best enemy: context: contacts in the social world (blame of others), losing social contacts attributing AN, alignment to therapists, condition; sharing the same SE-AN label
Process	Stages, phases, phasing's, transitions, passages, careers, chains, sequences	Several stages as if it is a chain reaction: During time, less contacts, the more attribution to the AN, According to attention of others; expressing concerns become expressing criticism,
Degree Family	Extent, level, intensity, range, amount, continuum, statistical average, standard deviation	Intensity: Intensity of fear of losing people, losing therapeutically alignment; highest attainable stage: Sanctuary
Type Family	Types, classes, genres, prototypes, styles, kinds	Types: (On the condition) guilt, blame, control, victim
Strategy Family	Strategies, tactics, techniques, mechanism, management	Strategy: To make it bearable: Attributing blame to master punishment and reward, reattribution AN to increase the QoL
Interactive Family	Interaction, mutual effects, interdependence, reciprocity, symmetries, rituals	AN creates interdependency to therapists, alignment to the service
Identity-Self Family	Identity, self-image, self concept self-evaluation, social worth, transformations of self	Creating a personification of the illness, adaptation of the illness
Cutting-point Family	Boundary, critical juncture, cutting point, turning point, point of no return	AN is sanctuary
Cultural Family	Social norms, social values, social beliefs	Social norms: non-acceptance of the SE-AN status, leads to stigma, criticism, losing contacts = less contacts within the social norms
Consensus Family	Contracts, agreements, definitions of the situation, uniformity, conformity, conflict	Compliance: acceptance of the SE-AN condition, indicates adaption, patients 'belong to a group', experience similarity and conformity, sharing the same safe place (in the head) Sharing the same values: rejecting the SE-AN label, adopting the SE-AN label

Appendix 10: Memo 17: Exploring and refining initial codings - Mabel

Memo 17: Exploring and refining initial codings - Mabel

The data studies: The effects of SE-AN in a woman who has had a difficult childhood, as influenced by the sexual mis-abuse in her child hood which started at the age 2, until she reached the age 16. Her parents consequently denied this mis abuse and always have kept the silence referring to the mis abuse. The participant didn't receive any help until the age 28.
During her life, she developed eating problems which started as an overeating problem, and at the age of 28, Mabel developed AN, anxiety- and mood problems, and furthermore, a low self-esteem.
As seen from my point of view, as her therapist, she meets the symptoms of a posttraumatic stress disorder. And it is presumed that the AN can be seen as a coping style in order to function with a complex post traumatic stress disorder.

The data suggests: The AN is a way to handle her right to exist. In every facet of her life, such as; in her married life, being somebody's wife, in social contacts, in family structures, and during her daily activities, in the context of the contact with the health care professionals, Mabel's AN is the only thing where she holds on to, as her AN condition controls every situation, and for Mabel it is predicable what her AN demands of her. Without her AN, she has no right to exist. AN seems to function for her as a way 'to be seen' by others. 'See me suffering'. (Mabel: L90; L93; L99)

The data also suggests: The participant uses the AN as a way to punish herself. This specific thought is provoked when she does not live to the rules the AN demands from her. In the context of Mabel's construct, punishment contains the following actions: Less eating, more exercise and more cleaning. It is seemly that punishment is connected to 'her right to exist', regarding the fact that others see her suffering.

Also the data suggests**:** A way of having contact with her husband, their conversations often are about eating /not eating/ exercising/ cleaning concerns. According to the construct of Mabel, the communication of this couple is 'through' the eating disorder cognitions and behaviours. (Mabel: L51; L78; L84; L120; L148).

Then, the data suggests: **Mabel's AN functions as a catalyst for her emotions, such as her grief against her family, related to the unpleasant experiences in youth. Without her AN condition, Mabel appeared to have no possibility in handling her emotions.**

This data is seen: From my point of view as a researcher and as an experienced therapist.

Findings of the spoken interview recordings and field notes:
During the interview, Mabel presented herself as a vulnerable woman. Her appearance conflicted with her real age, she appeared to be older than her real age (43). Mabel wore a hard plastic corset because the state of her osteoporosis demands it form her. Her posture impressed me such as she always have to wear a big burden all day long.
Mabel was very well prepared for this interview. Her mimicry was subtle and the tone of her voice appeared soft, which was normal in our conversations we usually had. I know her as one of my patients. And it took me some time to work on this level of trust. Thus, I considered that she was able to talk in confidence regarding her status of illness and her thoughts of it. (**This is also one of my personal underpinnings to interview women I am familiar with, it's difficult to interview women who do not know me well enough, after all, it might increase the change that the women participants will only please me and give me the answers they think that I would like to hear, not the answers where I was searching for).**

During this interview, she revealed some emotions which were provoked by the explanation of her personal situation.
However, it was always delicate, she gave me the impression that her grief was too difficult to show to other people. My thought of this phenomenon was: her background, and what other people have done to her, made it very difficult to express and share her emotions because it made her vulnerable. Furthermore, it was noticeable that her focus in this conversation was mostly of 'what the other people might think of her'. It was not what about how other people might affected her, or, even stronger, might have damaged her. This perception seems to cooperate with a deep persuasion of 'no right to exist'. In contact with Mabel, there was no room for a laugh of humour.

Main conclusion of the data set of AH:
A broad conclusion: **This data sets suggest that: *The AN gives Mabel an identity enabling her to handle her emotional, the psychological and the physical pain. For Mabel, the AN condition functions as a modus in daily life, Mabel receives direct attention through the AN. Furthermore, her AN functions not only as a catalyst in discussing emotions, it suppresses her emotional experiences.***

In the exploration of Mabel's data set, I started by defining the initial coding's (the early codes) which made the data significant and thus, grounded. The initial codes are written in gerunds which are helpful in to stick to the data and to detect the processes (Glaser, 1978 in Charmaz, 2006 p 49).

Initial codings: Punishing, the ED is providing contact with husband, experiencing eating rules, experiencing guilt, being seen

Excerpts
Mabel: L51: "The only understanding I receive is from caregivers and my husband. He understands it a little bit. But even then…"
Initial codes: 'The ED is providing contact with husband', and 'Receiving understanding from others of her situation'.

Mabel: L55: "I try to find affirmation, like, that I'm not crazy at all, otherwise, it ends up in less eating as a punishment. I have to punish myself by obsessed exercising and cleaning".
Initial codes: 'Defining eating rules', 'defining punishment', 'less eating', and, 'obsessed exercising and cleaning'.

Mabel: L78: "I'm very shy, but at the same time, I loose myself in talking to others, I cross my boundaries by talking. That's what happened last week. Finally, I've had myself through, I noticed by myself and said it to my husband; this is not going to end well. I was talking too much, talking about nothing but I felt the stress. I couldn't stop. That was the point of notice; something is wrong. I asked my husband if he wants to help me stop talking, because, I couldn't hold it any longer. But that's one side, the other side is that I say nothing at all, that's also what happens very often".
Initial code: 'The ED is providing to have contact with my husband'.

Mabel: L84: "I see how it works, and I don't want to prohibit my husband to eat a nice snack or someone else in my environment, to eat a cookie or something like that, even if I can't. I simply can't say: don't do that".
initial codes: 'The ED is providing to have contact with my husband, and 'Defining eating rules'.

Mabel: L86: **"**My focus is eating**,** exercise, once; if I need to take some rest, I don't like it if somebody exercises meanwhile. An example, if somebody goes for a stroll and I can't go with him or her, I feel very guilty. I feel guilty by lying on the cough or in bed. Like, someone else is doing something what I need to do. If I take that load, I make it possible for the other that he or she can take some rest.
Initial codes: 'Experiencing guilt', 'Defining eating rules', Focusing on eating', and 'Earning to rest'.

Mabel: L90: "Q; Do you feel less important that the other?
Yes, that's what I feel. I 'm not important, for nobody. I am nothing**".**
Initial code: 'Being nobody'.

Mabel: L93: "I'm good enough for decoration. And I don't like it to get presents, I feel so unsure. I think by myself, let's get it over with that. It's not necessary. I always asked myself; why do give people presents to me? I am a burden. I don't deserve that, never".
Initial code: 'Being a burden for others'.

Mabel: L99: "If there's happening something good, I always think; that's not good, what's going to happen now? What kind of evil message is there for me?"
Initial code: 'Experiencing hostility'

Mabel: L120: "I don't know exactly, I know wherefore I eat, for a better quality of life, so I need the pressure, once that's gone, I don't think that I will eat anymore. If I wasn't married I think that I was ready with this life. We'll see what's going to happen, even if I will die on it. But I love my husband and he loves me, so it's worthy to try it for him. I do my best for him".
Initial codes: 'Defining the value of life with the AN condition', 'Defining eating rules', 'Defining the love for my husband'.

Mabel: L148: "I see what people do with it and how the television handle the disorder. Last Wednesday, We've watched a TV program. It was a program were a woman had a weight loss of 15 kilos, in the eyes of the makers she was healthy then, However, she wanted to loose more weight, again 15 kilos, and, this woman would do everything for that goal. However, there was a dietician, she said; it isn't necessary to loose more weight, but still, program kept on giving attention to the woman, my husband said: "this is a dangerous point".
Initial code: 'The ED is providing to have contact with my husband'.