

**Accounts of the impact of erectile dysfunction  
on heterosexual couples from men seeking  
erectogenic treatment and their partners**

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**A thesis submitted in partial fulfilment for the requirements of the  
Degree of PhD at the University of Central Lancashire**

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**Accounts of the impact of erectile dysfunction on heterosexual couples  
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**Abstract**

**Introduction:** Erectile Dysfunction (ED) is known to impact on the lives of men but few studies have sought to assess the impact of ED on women and there are no qualitative studies that have compared accounts from women and their partners on the impact of ED on the relationship. Current trends in prescribing of ED treatment focus on men and consider ED to be a male medical problem.

**Aim:** The aim of this study was to obtain knowledge on how ED affected the lives of women and their partners and to gain insight into the impact of ED from a couple's perspective.

**Methods:** Qualitative accounts from women on the impact of ED were obtained from one to one semi structured interviews and from clinical interviews with their partners. Interviews were audio taped and tape recordings transcribed. The study sample consisted of heterosexual couples and compared feedback on the impact of ED from interviews with men seeking erectogenic treatment and their partners. Men attended routine appointments at a secondary care specialist clinic following referral to the clinic by their GP and were interviewed. Feedback from interviews with men was recorded in hospital case-notes. Men with severe ED that met the inclusion criteria were invited to participate in the study and if they agreed were asked to deliver information about the study to their partners. Interview appointments were arranged for women that agreed to participate in the study and informed consent was obtained from both partners. Transcriptions of

interviews with women were analysed using grounded theory. The size of the population sample was dictated by the theoretical relevance of the data in relation to the research enquiry. New concepts and new avenues of enquiry ceased to emerge from analysis of transcriptions after fifteen interviews.

**Results:** Women expressed that ED consumed their partners and reported that their partner's perception of "solving the problem" focussed on restoration of erectile function. These data were verified by men. Women expressed that they attempted to confront "the problem" by encouraging their partners to seek help but men delayed seeking help due to embarrassment. Women felt isolated and upset at the lack of reciprocity and struggled to make sense of their partner's perspective, as men communicated to women that the sexual act was of optimum importance in terms of defining the relationship. Men expressed concern that their partners might seek sexual activity "elsewhere" which reinforced perception among women that men defined the relationship in terms of sex. Women were concerned that ED was a symptom of an underlying condition yet men ignored their advice to seek help. Erectile dysfunction affected men's confidence and caused lack of self esteem. Men reported that ED impacted on their masculinity. Women expressed that ED caused significant disruption to their lives and agreed to their partners using treatment if it was likely to improve their quality of life by having a positive effect on their partner's mood.

**Conclusions:** Women were aggrieved and disappointed that ED had such a devastating influence on their relationship. The emotional trauma that women experienced and expressed suggested that feelings of hurt might prevail regardless of treatment outcomes. Women were disappointed that the bond in their relationship was weakened by ED and their partner's reluctance to communicate. Men expressed fear of "losing everything" and

felt that restoration of erectile function would solve all of theirs and their partner's problems. Lack of communication resulted in men and women relying on perception of how ED affected their partners. Although this study did not provide solutions to the problems that couples experienced it produced data that was unique in terms of insight into the impact of ED on women and their partners and identified the importance of considering the couple's perspective on the problem when assessing ED. Further research is required into the impact of ED on couples as understanding of how ED impacts on a couple's relationship is poor.

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## **Chapter 1**

### **Background and experience**

#### **Introduction**

In this opening chapter I summarise the reasons why I chose to undertake this study. I explain why previous research that I conducted into ED and its treatment is relevant to this study and I discuss the influence of current trends in prescribing of ED treatment on my decision to look at the impact of ED on women. I then discuss the study title and I explain why I chose to conduct a qualitative study. I discuss the influence of my clinical experience on formulation of the research question and I present an outline of the structure of the thesis.

#### **Background to the study**

Current trends in prescribing of erectogenic treatment neglect partners of men with ED and promote the notion that ED is a male medical problem (Riley, 2008). Since the launch of user friendly oral treatment for ED GPs have been encouraged to take an active role in prescribing erectogenic treatment (Dean et al, 2008). Although this has improved access to treatment for men with ED by avoiding referral to a secondary care clinic it is thought that time restraint has influenced GPs to neglect the importance of considering ED from a couple's perspective (Brock et al, 2007). GPs have been encouraged to use the Sexual Health Inventory for Men (SHIM) to assess ED which is a short form version of the International Index of Erectile Function (IIEF). The IIEF is the most widely used psychometric assessment in studies of ED and its treatment (Goldstein et al, 1998;

Padma-Nathan and Giuliano, 2001; Rosen, Cappelleri and Gendrano, 2002; Stuckey et al, 2003; Porst et al, 2003; Montorsi et al, 2004; Porst et al, 2006; Eardley, 2006). The SHIM is a self assessment questionnaire and may help men with ED communicate with GPs about the problem. The SHIM is similar to the IIEF in terms of promoting biased assessment of erectile function and neglecting other aspects of the male sexual response (Kloner et al, 2003).

Prior to conducting this study I completed a Masters Degree in Sexual Medicine at the University of Central Lancashire. My MSc research assessed the sensitivity of the IIEF in terms of its ability to identify compromise in the male sexual response. The results of this study influenced my opinion that assessment of ED was limited if the potential impact of ED on the couple was not considered.

#### IIEF assessment of sexual function

The IIEF was introduced following recommendation of the National Institute of Health (NIH) in 1993. The NIH, via a consensus conference, advised that a reliable method of assessing ED and its treatment was required, as existing methods of measuring male sexual function and efficacy of ED treatment were considered to be inadequate. The IIEF has been widely used to measure efficacy of sildenafil citrate (Viagra) and other oral treatment for ED and when introduced it established a new approach to assessment of ED (Rosen et al, 1997; Pryor, 2002; Brock, 2002; Porst et al, 2003; Montorsi et al, 2004; Rubio-Aurioles et al, 2009; Kaminetsky et al, 2009; Althof et al, 2010).

The IIEF includes 15 items that collectively address erectile function, orgasmic function, sexual desire, relationship satisfaction and overall satisfaction (Rosen et al, 1997). There is also a Global Efficacy Question (GAQ) which asks if treatment improved erectile function (Stuckey et al, 2003; Porst et al, 2003; Montorsi et al, 2004; Porst et al, 2006;

Eardley, 2006; Tolra et al, 2006; King et al, 2007; Farca et al, 2008; Cappelleri et al, 2008; Edwards et al, 2006). The GAQ is restricted to “yes” or “no” responses and has been used to determine treatment success in many studies (Tolra et al, 2006; King et al, 2007; Farca et al, 2008; Cappelleri et al, 2008). The IIEF has been used almost exclusively in quantitative research into ED treatment and has measured treatment success on the basis of baseline to endpoint scores from each of the 5 IIEF domains (Goldstein et al, 1998; Padma-Nathan and Giuliano, 2001; Rosen, Cappelleri and Gendrano, 2002; Stuckey et al, 2003; Porst et al, 2003; Montorsi et al, 2004; Porst et al, 2006; Eardley, 2006).

The study I conducted for my MSc assessed the sensitivity of the IIEF in terms of measuring ejaculatory function, sexual drive and orgasmic sensation. I developed and validated a new questionnaire, the Index of Male Sexual Function (IMSF). The IMSF is specific to assessment of ejaculation, sexual drive and orgasmic sensation (Rutherford, 2004). In a randomised, blind, crossover study I assessed efficacy of sildenafil citrate (Viagra) and apomorphine hydrochloride (Uprima). Thirty five men with ED participated in the study and completed IIEF and IMSF questionnaires at baseline, crossover and endpoint (12 weeks). Individual IIEF and IMSF scores were compared at baseline and after completion of each treatment (Rutherford, 2004). Crossover was preceded by a 2-week washout period. Analysis of individual scores revealed that the IMSF identified patients that continued to experience problems with ejaculation and orgasmic sensation regardless that they reported improvement in their erectile function. My research findings suggested that the IIEF was weak in terms of its ability to measure sexual drive, ejaculatory function and orgasmic sensation. The IIEF includes only 6 questions on sexual desire, sexual satisfaction and relationship satisfaction. Five IIEF questions are specific to assessment of erectile function (Rosen et al, 1997). These data suggest that the IIEF considers measuring sexual desire, sexual satisfaction and

relationship satisfaction to be less important than measuring erectile function.

The IIEF remains the most widely used assessment criteria in studies of ED and its treatment (Farca et al, 2008; Cappelleri et al, 2008; Edwards et al, 2006; Kamenov, 2010; Porst et al, 2010; Iacono et al, 2010). Although it neglects enquiry into the predicament of partners of men with ED the IIEF has been used to assess opinion on treatment of ED in studies that included couple samples (Cayan et al, 2004; Wiegel, Meston and Rosen, 2005; Althof et al 2006; King et al, 2007; Farca et al, 2008; Cappelleri et al, 2008).

### **Clinical experience of the author**

I completed my nurse training in 1986 and was successful in my application for a staffing post in a busy urology ward and I became interested in andrology and sexual medicine. In 1993 I was asked by a consultant diabetologist to provide treatment for men with ED and diabetes which coincided with the introduction of intracavernosal alprostadil (Caverject), the first drug to be licensed to treat ED (Stackl, Hassun and Marberger, 1988). Promotion of Caverject by its manufacturer (Pharmacia and Upjohn) included financial endorsement of specialist clinics and development of services for men with ED.

Prior to the introduction of medical therapy structured NHS services for men with sexual problems were rare and private services were expensive. Treatment for organic ED, prior to medical therapy, was restricted to vacuum tumescence devices and surgical prosthetic penile implants and there was little demand for such invasive and mechanical treatments (Derouet and Zehl, 1993; Lewis and Worthington 1997; Montague and Angermeier, 2000; Morales and Heaton, 2002). The introduction of intracavernosal alprostadil raised awareness of ED and increased interest in erectogenic treatment (Stackl, Hassun and Marberger, 1988; Porst, 1997a, p 185-189; Shabsigh et al, 2000).

Sildenafil citrate (Viagra) was launched in September 1998 and the government responded by introducing guidance that was designed to restrict prescribing of medical treatments for ED on the NHS (Adam, 1999b). The Department of Health provided no additional funding to cope with the demand for Viagra and due to the financial consequences of an increase in referrals to my clinic debate ensued about maintaining a secondary care specialist service for men with sexual problems. In 1999 I presented a cost benefit analysis document to the NHS Director of public health that highlighted the potential consequences of neglecting to provide assessment and treatment for men with sexual problems. National figures on the cost of prescribing ED treatment between 1997 and 2000 highlighted that although specialist consultations for men with ED increased by 12% the cost per patient of specialist assessment and treatment decreased significantly (Wilson et al, 2002).

Prior to the introduction of medical therapy ED treatment including vacuum devices and surgical penile implants were provided by urologists, which influenced opinion that urology services would, by default, continue to provide treatment for ED regardless of the increase in demand for more user friendly treatments (Berger, 1998; Montague, 2002). Resource implications in terms of coping with demand for treatment influenced debate on who should treat ED regardless that penile disorders were historically considered to be urological problems (Porst, 1997a, p 175-192; Kell and Dinsmore, 1997; Burnett, 1998).

In March 2005 I attended a meeting in Rome to provide opinion on a marketing campaign that had been design by a pharmaceutical company to promote medical treatment for ED. A group of 32 specialists in sexual medicine from 18 countries were asked to comment on a presentation on the company's marketing ideas. The presentation

promoted the notion that ED treatment influenced better sex regardless of whether compromise in erectile function had been identified. It also encouraged men to question their sexual function and neglected assessment of ED from a couple's perspective. Although feedback from the audience of specialists was largely negative and highlighted that subjective assessment of ED was neglected the organisers made no plans to change their marketing strategy. Evidence from a study subsequent to the meeting suggested that the pharmaceutical company adhered to promoting their drug by highlighting the prospect of "better sex" (Mulhall, Levine and Jünemann, 2006).

During clinical interviews men often identify that ED impacts on their masculinity and often state that they no longer consider themselves to be a man. The impact of ED on masculinity motivates men to seek help but also causes embarrassment and men often express that their reluctance to discuss the problem was influenced by the prospect of admitting that they were unable to function as a man. Erectile dysfunction has been linked to depression (Araujo et al, 1998; Seidman, 2002) and although men with ED present with low self-esteem and lack of confidence I have encountered few men that have been prescribed treatment for depression that was thought to be influenced by ED. Men with ED often neglect to seek help regardless that ED negatively affects their mood and their ability to communicate with their partners about the problem. Prior to conducting this study clinical interviews provided limited information from partners on the impact of ED.

Following completion of my MSc I met with my Director of Studies, Professor Alan Riley, Professor of Sexual Medicine at the University of Central Lancashire (UCLan) and discussed the limitations of my MSc research. Absence of information on the impact of ED from partners of the men that participated in my study was identified as a major

weakness. Both the IMSF and the IIEF neglected partner issues. In 2005 subsequent to completion of my MSc I conducted a literature review to obtain information on how ED affected men and their partners and I found that the opinion of partners on ED and its treatment was largely neglected.

In 2006 prior to designing this study I carried out a retrospective audit of feedback from 119 clinical interviews that I conducted with men seeking treatment for ED. I routinely record detailed information from clinical interviews in the patient's case-notes. Feedback from the audit identified that men with ED provided accounts on how ED affected their partners but also acknowledged that they avoided discussion about the problem with their partners and rarely included their partners in treatment decisions. Only 7 out of 119 referral letters for these men mentioned the patient's partner or identified that ED was causing relationship problems.

### **The study title**

The study title highlights that I obtained accounts from couple samples on the impact of ED and explains that my research focussed on heterosexual males and their partners. The study title explains that I recruited men that were seeking treatment for ED, which suggests that men considered ED to be problematic. When planning this study my initial intention was to obtain information on the impact of ED on women in order to develop a psychometric questionnaire that was specific to heterosexual couples. Feedback from the literature review identified gaps in the literature in terms of how ED affects women and their partners and changed my opinion on my research objectives. My research proposal had gained ethics approval when I changed the focus of my research and the study title. I contacted the West of Scotland Central Office for Research and Ethics and informed them of the change. I did not change any other aspect of the study design therefore my

request to change the study title was approved and the amendment was recorded and attached to my initial approval documents.

The study title explains that I obtained accounts of the impact of ED on men seeking erectogenic treatment and their partners. It reflects that although I came to the research with ideas and opinions about the impact of ED on women my opinions were influenced by information I obtained from interviewing women in the presence of their partners. I obtained information on the impact of ED on men from the literature review and compared the results with the opinions I had formed from clinical experience although this information was incomplete as information from the literature focused on ED from a man's perspective. I interviewed men and recorded feedback by writing notes and I compared notes from interviews with men with information I obtained from interviews with their partners. I discuss the study design in detail in chapter 3.

The study title "Accounts of the impact of erectile dysfunction on heterosexual couples from men seeking erectogenic treatment and their partners" links the research question to the study design and focuses on subjective opinions of women on the impact of ED.

### **Formulating the research question**

The research question was refined from opinions and theories I formed from clinical experience and feedback from the literature review on assessment and treatment of ED. As I gained knowledge and experience in sexual medicine I realised the importance of accurate and thorough assessment (Rutherford, 2004). I considered the consequences of ED in terms of how it affected couples. Clinical interviews with couples provided information from a joint perspective whereas information from clinical interviews with men neglected their partner's opinion on the problems associated with ED.

My research enquiry was designed to provide insight into the impact of ED on women whose partners had sought erectogenic treatment and the key research question was “What affect does erectile dysfunction have on women whose partners experience ED and consider ED to be problematic?” All of the men that I recruited into the study identified that ED was problematic. The research question was influenced by my clinical experience, as clinical interviews on the impact of ED provided feedback that was biased towards the impact of ED on men and the literature review provided limited information on the affect of ED on women. I wanted to recruit a sample of women whose partners experienced significant decline in their erectile function in an attempt to avoid conflicting opinion between men and their partners on the severity of ED. I used the IIEF Erectile Function (EF) domain scores in the inclusion/exclusion criteria to identify severe ED prior to recruiting men into the study. The IIEF defines severe ED as the persistent inability to obtain an erection that is sufficient for sexual activity (Rosen et al, 1997).

I wanted this study to provide information on how men reacted to the affect of ED on their partners. My research enquiry was designed to look at women’s perceptions of ED and its consequences, to obtain information from women on erectogenic treatment and to compare feedback from women with information on the impact of ED from interviews with their partners.

### **The structure of the thesis**

Chapter 1 is an introduction to the thesis. I explain the background influences on my decision to conduct this study. I discuss the relevance of my clinical experience in terms of influencing my opinion on assessment and treatment of ED. I then explain the relationship between my research objectives, the study design and the study title and I

discuss the process of formulating the research question. I explain the importance of the research question in terms of defining my research enquiry. I end chapter 1 by describing the structure of the thesis.

Chapter 2 (the literature review) begins by discussing the impact of ED on men including its affect on masculinity. This chapter then examines the penis and its symbolic connotations in terms of defining masculinity. I then look at the history of treatment for ED prior to the launch of sildenafil citrate (Viagra). Chapter 2 goes on to look at the epidemiology and aetiology of ED in relation to marketing of ED treatment. I discuss the history of ED treatment following the launch of sildenafil citrate (Viagra) and the influence of Viagra on current prescribing of ED treatment. I then look at treatment efficacy. Chapter 2 goes on to discuss the influence of oral therapy on medical opinion on ED and its treatment. I then look at the reasons why women are excluded from assessment and treatment of ED. I discuss the medicalisation of sex and the restrictions on prescribing ED treatment on the NHS. I then highlight relationship issues associated with the impact of chronic disease on couples and I conclude the chapter by discussing gaps in the literature review that influenced my research question and study design.

Chapter 3 provides a detailed description of the study design and explains why I chose qualitative research methodology. I then go on to discuss recruitment of the population sample and I explain the reasons why I chose one to one interviews to collect data from women on the impact of ED. Chapter 3 goes on to explain why symbolic interactionist theory related to my research. I then discuss the reasons why I chose grounded theory as a method of data analysis and I describe the process of coding data and developing concepts into key themes. I then discuss theoretical sampling of concepts to test the relationship between the emergent theory and the phenomenon of interest.

Chapter 4 concentrates on the results. It explains data saturation in terms of identifying the size of the population sample and presents demographic details of the participants. I then discuss feedback from the interviews I conducted with men and I go on to present the results of interviews with women. I then compare opinions from women and their partners on the impact of ED

Chapter 5 focuses on reflexive enquiry and defines the importance of reflexivity in terms of this study. I discuss the influence of gender on feedback from research interviews and I look at the influence of my opinions and perceptions on my interpretation of the data. I look at the many background variables that may have affected the opinions women and their partners expressed when participating in interviews. I consider the influence of my gender, my attire, the environment, my physical appearance and my professional role on my interpretation and analysis of the data and I go on to discuss the limitations of my research enquiry.

Chapter 6 begins by looking at the reasons why ED is considered to be a male medical problem and goes on to discuss action strategies that may increase the prospect of ED being considered from a couple's perspective. I elaborate on the relationship between symbolic interactionist perspective and interactions about sex. I then discuss the relevance of this study in terms of providing new knowledge on the impact of ED on women and their partners. I consider the importance of "normal" sexual function and I discuss the problems that may manifest from poor communication between men with ED and their partners. I then look at the significance of this study in relation to my clinical practice and I discuss my research findings in relation to feedback from the literature review.

Chapter 7 presents my research conclusions and I discuss my findings in relation to the research question. My conclusions discuss my research in terms of its contribution to the literature. I identify gaps in knowledge that have not been addressed and the questions my research raised. I discuss future research that is required to add to the knowledge gained from this study and I then express my final thoughts.

## **Chapter 2**

### **Literature Review**

#### **Introduction**

This chapter includes discussion on feedback from the literature review including the impact of ED on masculinity, the symbolic nature of the penis and the role of the penis in the defining of man. A review of the history of ED treatment prior to the introduction of sildenafil citrate (Viagra) is provided prior to looking at the epidemiology and aetiology of ED and marketing of ED treatment. This chapter then goes on to review the history of ED treatment following the launch of sildenafil citrate (Viagra) and provides information from the literature review on assessment of ED and measurement of treatment efficacy. I then discuss the influence of oral therapy on treatment for ED, opinion from the literature review on the classification of ED in terms of disease taxonomy and I look at the possible reasons why ED is considered to be a male medical problem. Subsequent discussion in this chapter includes ED and its relationship with the medicalisation of sex and society and the influence of politics on assessment and prescribing of ED treatment. This chapter then goes on to look at the impact of chronic disease on the lives of women and their partners in order to gain insight into how couple's adjust to living with a chronic condition and compares these data with information on how couple's adjust to living with ED. The chapter concludes by identifying gaps in the literature in relation to my research enquiry.

#### **The impact of ED on men**

Studies of the impact of ED on men have concentrated on measurement of sexual function, sexual satisfaction and relationship satisfaction prior to and post ED treatment using quantitative research methods (Goldstein et al, 1998; Padma-Nathan and Giuliano,

2001; Rosen, Cappelleri and Gendrano, 2002; Cappelleri et al, 2004; Stuckey et al, 2003; Porst et al, 2003; Montorsi et al, 2004; Porst et al, 2006; Eardley, 2006; Cappelleri et al, 2008). Research has found that ED adversely effects the quality of life of men and causes lack of confidence and depression (Fugl-Meyer et al 1997; Porst 1997b, Seidman et al, 2001, MacDonagh, Porter and Ewings, 2002; MacDonagh et al, 2004; Seftel, Sun, and Swindle, 2004; Sand et al, 2008) although there are no studies that have looked at the impact of ED on couples lives by obtaining qualitative accounts from couple samples.

It has been reported that a large percentage of men with ED choose to avoid discussing the problem because of embarrassment (Levine and Kloner, 2000; Baldwin, Ginsberg and Harkaway, 2003; Solomon, DeBusk and Jackson, 2005) but there are no studies that have looked at how reluctance among men with ED to communicate with their partners or to seek help affects the real life experiences of couples. Men have reported that ED has caused them to avoid intimacy with their partners, become less assertive and to feel withdrawn from society (De Busk and Jackson, 2005; Fisher et al, 2005b; Fisher et al, 2009). Although these studies have looked at how ED affects men there are no qualitative studies that have compared opinions on the impact of ED on couples.

Although ED is thought to affect masculinity (Potts, 2000; Oliffe, 2005; Fisher et al, 2004) there is limited information on how the impact of ED on masculinity affects the lives of men and their partners (Sand et al, 2008). Understanding of the relationship between ED and demasculinisation is poor although it is reasonable to suggest that if ED causes men to become withdrawn and avoid intimacy with their partners assessment of the problem is likely to be limited if it is not considered from the couple's perspective. Historically masculinity has been associated with sexuality and sexual function (Bem, 1974; Spence, 1991; Kaplan, 1993; Spence and Buckner, 1995) although opinion on what

defines masculinity may have changed, as it has recently been suggested that men consider sexual function to be less important in terms of being masculine (Bem, 1981; Sand et al, 2008). It is thought that in order to understand masculinity it is essential to understand the constructs of femininity (Bem, 1981; Stern, Barak and Gould, 1987). Due to variation in the personal characteristics of men and women it has been reported that the constructs of masculinity and femininity are part of the same bipolar continuum with the potential for interaction and fluctuation between the two poles (Bem, 1981, Spence, 1991). This theory suggests that men and women might display characteristics that are more likely to be associated with the opposite gender (Bem, 1981; Spence, 1991; Palan, Areni and Keicker, 1999). In a study by Sand et al (2008) on the constructs of masculinity, men with ED identified that obtaining an erection was not considered to be of great significance in terms of defining masculinity. Global sales of Viagra may challenge this opinion (Lexchin, 2006). Perhaps the impact of ED on men influences change in terms of where men see themselves on the bipolar continuum or perhaps sexual function is less important in terms of defining masculinity in a society that is reported to have addressed the issues of gender inequality (Sedacca, 2002; Sowards and Renegar, 2004; Pinker, 2008; Lloyd, 2010).

In his definition of masculinity Aristotle included independence, assertiveness, instrumentality, and competitiveness whereas women were thought to possess qualities such as, understanding, caring, nurturance, responsibility and considerateness (Witt, 2004; Mahowald, 2009). Other definitions of masculinity and femininity are similar (Spence, Helmreich and Stapp, 1975; Cross and Markus, 1993, p 58-98). It has been suggest that women are more likely than men to display qualities such as being aware of others, establishing a state of interdependence through communication and the ability to facilitate interaction whereas gender identity traits among men are reported to include,

separating the self from others, being concerned for the structure and functioning of the self and manipulating people to perform tasks (Gill et al., 1987; Jordan, 1991, p 82-83). The impact of ED on men may include “concern about the structure and the functioning of the self” and the consequences of being unable to function may have a negative impact on traits such as assertiveness and confidence, resulting in “separation of the self from others” including wives and partners (Fisher et al, 2005b; Sand et al, 2008).

### Roles according to gender

The impact of ED on femininity may not have been considered as historically women have not been encouraged to believe that “knowing the truth about their sexuality was important” (Hite, 2004, p 11). Western patriarchal society has suppressed women’s perception of their sexuality (Glick and Fiske, 1994; Glick and Fiske, 2001; Witt, 2004; Mahowald, 2009). Aristotle’s definition of a citizen is thought to have included the verdict that a “female is a misbegotten male” (Rhode 1996, p 22) and although allegedly written in 320 BC, the concept of the “misbegotten male” is often cited during discussions about gender inequality (Elshtain, 1974; Dietz, 1985; Rhode 1996, p 22; McNeil, 1999).

In 2009, Father Robert Busa’s affiliation to Aristotle’s beliefs, via St Thomas Aquinas’ “Summa Theologica”, which asks whether woman should have been made in the first production of things (On Generation and Corruption, Book 2, Part 3) inspired internet debate on the influence of Aristotelianism on today’s society (Crawley, 2009). Analysis of Aristotle’s logic has reached varied conclusions although opinion that suppression of women in Ancient Greece has influenced current issues of gender inequality is conclusive (Elshtain, 1974; Miller, 1995; Rhode 1996, p 22; Witt, 2004; Mahowald, 2009; Crawley, 2009). According to Aristotle a “citizen” was more than just a denizen or a

dweller but certainly not a woman. Women were considered to be intellectually inferior to men. Aristotle described a “citizen” as “a man” who was capable of forming and expressing logical and rational political views (Jayapalan, 2002, p 115-121). Women were collectively regarded as being incapable of operating within such a sphere of responsibility. Although Aristotle’s “misbegotten” opinion is not politically correct in its representation of western democracy, in reality suppression of women remains evident despite political propaganda suggesting that gender inequality in homogeneous society is being eradicated (Klima, 2001; Sowards and Renegar, 2004; Pinker, 2008). Exclusion of women from assessment and prescribing of ED treatment and lack of knowledge on the impact of ED on femininity reflects current perceptions of how important it is to consider women when prescribing treatment to restore their partner’s erectile function.

Saint Thomas Aquinas (Summa Theologica 1265-1274, Question 92, Article 1, 1920) response to the question “should women have been made in the first production of things?” reinforces Aristotle’s views and provides evidence of gender inequality and suppression of women in 13<sup>th</sup> century Europe. Aquinas suggested that females would have been left wanting if not governed by men and that women were “naturally subject to men because in man the discretion of reason predominates”. The opinions of Saint Thomas Aquinas continue to influence segments of society and are considered sacred by devout members of the Catholic Church (McInerney, 1992).

In the 18<sup>th</sup> century Mary Wollstonecraft’s (1792) writings on the vindication of women, although stifled by patriarchal dominance and the political systems that she deplored were integral to the creation of the women’s rights movements that swept throughout western society in the late 19<sup>th</sup> and early 20<sup>th</sup> centuries. Wollstonecraft’s (1792) opinions on citizenship challenged the fathers of reason (Aristotle and Plato) and her opinions on

why women were equal to men were presented in deliberate hybrid tone and adhered to the principles of Aristotle's logic which made her views difficult to challenge. Mary Wollstonecraft (1792) expressed that reason, logic and intellect were asexual, spiritual qualities that transcended the politics of inequality and disparity. Although modern day opinion on the constructs of masculinity and femininity vary (Spence and Buckner, 1995; Sand et al, 2008) the views of Aristotle continue to influence values and beliefs of men and women in western society. Although society has become more civilised, historic descriptions of social evolution might have been fabricated by the despotic authoritarian figures that wrote our history books. Aristotle's logic provided the foundations of what now defines us as men and women. Feminist movements in western patriarchal societies have been successful in establishing legal precedence for women's rights yet gender inequality remains evident despite political rhetoric that suggests otherwise (Strathern, 1990, p xii; Pinker, 2008; Lloyd, 2010).

### The symbolic nature of the penis

Historically and in many cultures, the penis (often erect) has represented hegemonic masculinity (Vanggaard, 1972; Harris, 1998; Loe, 2001) and has been depicted throughout the ages in various artworks, as a sign of vitality, aggression, power and fertility (Gombrich, 1954; Vanggaard, 1972; Dalure, 1975; Stephens, 2007). In modern literature and often in the media the penis is referred to as "manhood" which suggests that it is integral to the defining of man (Tiefer, 1986; Ollife, 2005; van Driel, 2009). Perception of penile size has created significant psychological problems for men (Drummond and Filiault 2007). In recent times an increasing number of men have requested surgical enhancement of penile size regardless that most of these men have "normal" penile length and girth (Vardi et al, 2008). Internet problem pages have been inundated by men that are worried about establishing relationships due to the notion that

their penis is small and inadequate (Men's Health Forum, 2010).

Anonymity encourages men to disclose their apprehensions and fears about sexual function and the internet opens discussion to a global population of participants. The internet, however, may influence feelings of inadequacy as participants in on-line pornography are likely to be men that are well endowed, which encourages unrealistic perception of a "normal" phallus (Megget, 2007). The desire to be "normal" is often the source of "the problem" and this situation may apply to men seeking help for ED and other sexual problems. Pursuit of normal is often influenced by unrealistic expectations (Megget, 2007) and media advice that influences unrealistic expectations of erectile function is often targeted at men and disregards their partners (Lexchin, 2006)

Micro-penis (a penis of < 2.8cm in length) is thought to have a negative influence on a man's social and psychological development and men that believe their penis is below average size lack confidence in terms of establishing relationships (Lee et al, 1980; McMahan, Kramer and Husmann, 1995; Men's Health Forum, 2010). Although genital surgery such as vasectomy is thought to have no physical consequences in terms of its effect on sexual function the impact of genital trauma on perception of body image may provoke psychological inhibition of the sexual response (Buchholz et al, 1994). Potts (2000) suggested that "by relinquishing the penis's executive position in sex men can become differently inscribed and coded for diverse pleasures beyond the phallus" which implies that an erection may not be required to achieve sexual fulfilment. The demand for ED treatment suggests that men disagree with this theory (Lexchin, 2006) and feedback from women in a study by Vares et al (2007) highlighted that penile tumescence was important to women in terms of achieving sexual satisfaction. The media suggests that sexual prowess is a major component of what defines a "man" (Gunter, 2002, p 67). Male

sexual prowess, according to the media, includes the ability to obtain a full erection, have sexual intercourse frequently and maintain sexual performance regardless of the circumstances (Gunter, 2002, p 278). Unrealistic expectations of male sexual function may influence men to seek erectogenic treatment (Lexchin, 2006).

### **Treatment of ED (pre Viagra)**

Historical opinions on the approach to assessment and treatment of ED may have influenced current trends in the prescribing of ED treatment and may have contributed to opinion that ED is a male medical problem.

In the nineteenth century medical authority considered that “normal” sexual activity was exclusive to heterosexual, monogamous sexual relationships (Weeks, 1985, p324). Homosexuality and many esoteric paraphilias were deemed to be unacceptable perversions and categorised as sexual deviations (Weeks, 1985, p 324) and in the early twentieth century homosexuality and masturbation were considered to be sexual problems (Pullias, 1937; Mertz, 1955; English, 1957). Prior to the 1950s the term “impotence” was used to identify male sexual problems although the term was vague as it referred to all aspects of the male sexual response including ED, ejaculatory disorders and decline in sexual drive (Ballenger, Elder and McDonald 1936; Bergler, 1937; Bergler, 1940; Creevy and Rea, 1940; Munro, Horne and Paull, 1948). Although these journal articles highlighted various sexual problems that were specific to men there was no mention of assessment and treatment of ED and no reference to the impact of male sexual problems on women.

The church provided consensus on “normal” sexual practice with heterosexuality and monogamous marriage being defined as acceptable and those that deviated from these

criteria were punished (Northcote, 1916; Hiltner, 1953; Bailey, 1959; Bailey, 1962; Hornstein and Faller, 1964; Peiss, 1986, p 244; D'Emilio and Freedman, 1988, p 428). In 1947 Alfred Kinsey published studies on human sexual behaviour (Kinsey, 1947). His work was groundbreaking in terms of producing new knowledge on human sexual interaction although Kinsey's research was nativist and biased towards his interpretation of his observations (Kinsey, 1947; Kinsey, Pomeroy and Martin, 1948; Kinsey et al, 1953). In the 1950s and 1960s research highlighted that sexual dysfunction often presented in men with organic disease (Thompson, 1950; Schwartz and Robinson, 1952; Walker and Strauss, 1954; Tuthill, 1955; Dahlen and Goodwin, 1957; Finkle, 1962; Bowers, Cross and Lloyd 1963; Reding and Ennis, 1964; Greenberg, 1965; Hierons and Saunders, 1966; Holtgrewe and Valk, 1964; Mann, 1968) although the prevalence of organic ED was not realised until the 1990s (Feldman et al, 1994).

Sexual problems in the 1950s were thought to be associated with personality disorders including disruptive selfish behaviour and inadequate moral sense (Strauss, 1950; Laidlaw, 1950; Stone and Levine, 1950; Freud, 1963). Assessment of impotence included Freudian psychoanalysis and was orientated towards identifying psychiatric illness (Freud, 1933; Laidlaw, 1950; Strupp, 1957; Freud, 1963). The stigma associated with mental illness discouraged men with ED from seeking help although public demand for literature on sex and sexual function increased. In 1956 "The Art of Loving" by Erich Fromm became an international best seller. Fromm (1956, Chapter 2, p 7-74) suggested that loving was a potentially learned skill and considering there were few publications to dispute his claims it is reasonable to suggest that many people purchased his book with great expectations. Fromm (1956) did not explain how to fall in love and there was no step by step guide on making love or establishing a loving relationship.

In the 1960s treatment for organic ED was established and included surgical implantation of costal cartilage although restoration of erectile function was rare (Chappell, 1952; Rusakov, 1964). Malleable prosthetic implants were introduced a few years later and combined with improvements in surgical techniques success rates increased (Pearman, 1967). These articles on penile implant surgery did not include subjective feedback from men and their partners although penile implant surgery is likely to have considerable implications for men and their partners in terms of accepting the prosthesis (Montague, 2002). The prosthesis may not be accepted by one or both partners therefore it is imperative that assessment prior to implant surgery includes couple counselling and facilitation of discussion between partners (Montague, 2002).

Prior to publishing “Human Sexual Inadequacy” (1970) William Masters concentrated his studies on female sexual function (Masters and Magallon, 1950; Masters, 1951; Masters and Grody, 1953; Masters, 1953; Masters and Ballew, 1955; Masters, 1955; Masters, 1956). In the late 1950s Masters and Johnson defined the stages of the female sexual response (Masters and Johnson, 1959; Masters, 1960; Masters and Johnson, 1960) and published detailed descriptions of vaginal anatomy and physiology (Masters and Johnson, 1961a) female orgasm (Masters and Johnson, 1961b) and the function of the clitoris (Masters and Johnson, 1962). Subsequent studies compared physiological differences in the male and female sexual response cycles (Masters and Johnson, 1965) which culminated in publication of “Human Sexual Response” (Masters and Johnson, 1966). Masters and Johnson changed medical opinion on sexual disorders and challenged the stigma associated with ED and other sexual problems. Their treatment plans focussed on a population of heterosexual, dual wage earning American couples and although nativist their work pioneered a new approach to sex therapy (Masters and Johnson, 1970)

At the centre of the Masters and Johnson (1970, p 317-318) therapeutic model were graphic depictions of the male and female sexual response cycle. Therapy was based on identifying problems by undertaking thorough assessment of the couple and considering the importance of the relationship dynamic in terms of influencing and treating sexual problem. Assessment was designed to encourage communication between sexual partners and feedback from women was considered essential in terms of developing a treatment plan. Sexual problems often manifested at different stages of the sexual response cycle in both partners therefore treatment was unique as it was tailored to the problems that were specific to each couple (Masters and Johnson, 1970, p 83-84). Therapy involved empowering couples with knowledge and improving confidence by relieving anxiety (Masters and Johnson, 1970, p 83-84) and sensate focus exercises were used to encourage intimate sexual contact and appreciation of sensation by focussing on non-genital sexual stimulation (Masters and Johnson, 1970, p 67).

Although the Masters and Johnson models of the sexual response cycle have been criticised their approach to dealing with sexual problems improved public awareness of sexual disorders (Clement and Schmidt, 1983; Gillan 1987, p 25-28; Tiefer, 1991). Public interest in the work of Masters and Johnson was confirmed by their appearance on the cover of TIME Magazine (TIME, 25<sup>th</sup> May, 1970) and both “Human Sexual Inadequacy” (1970) and “Human Sexual Response” (1966) became international best-sellers. Masters and Johnson’s version of the sexual response cycle was developed by other sex therapists to include sexual desire in order to identify desire disorders (Kaplan, 1974). The “resolution” phase of the male sexual response was considered by Kaplan (1979) to be a potential sign of ED and was not accepted as a natural phenomenon. Kaplan’s (1979) version of the sexual response cycle consisted of 3 phases including “sexual desire”, “sexual excitement” and “orgasm”. Like Masters and Johnson (1970) Kaplan (1974)

stressed the importance of couple counselling and assessment of feedback from both partners prior to embarking on a treatment program. Kaplan (1974) and other psychosexual therapists tailored sex therapies to the needs of the couple and introduced treatment plans that were designed to dispel sexual myths, reduce anxiety and influence realistic expectations in terms of treatment success (Annon, 1974; Blakeney et al, 1976; Leiblum, Rosen and Pierce, 1976).

In the 1990s Rosemary Basson (2001) introduced an alternative model of the sexual response cycle with added dimensions that attempted to explain the relationship between physiological and psychological aspects of male and female sexual function. Basson (2001) believed that Masters and Johnson's "Human Sexual Response" (1966) neglected the importance of emotional closeness and intimacy. Recent studies suggested that Basson's model was complex and difficult to understand and less appealing to couples than the Masters and Johnson (1966) and Kaplan (1974) models of the male and female sexual response cycle (Sand, Giraldi and Kristensen et al, 2010; Giraldi, Sand and Kristensen et al, 2010). Masters and Johnson (1970) reported outstanding therapeutic outcomes although there is little comparative research to substantiate their claims and no long term data on treatment success (Bancroft 1989, p 461; Rosen and Leiblum, 1995; Hawton, 1995). It is reasonable to suggest that sensate focus would have been of little benefit to men with severe organic ED although this argument fails to consider the potential benefits of including both partners in assessment of sexual problems and prescribing therapy that enhanced communication and reduced anxiety.

Masters and Johnson (1970, p 214-249) have also been criticised for focussing on vaginal intercourse when treating female orgasmic disorders despite reports that 70% of women require clitoral stimulation to experience orgasmic sensation (Hite, 2004, p 184). Other

critics expressed that Masters and Johnson's (1970) methodologies were regimented and unrealistic as therapeutic sessions were conducted on a daily basis (Gillan, 1987; Clement and Schmidt, 1983; Tiefer, 1991). Masters and Johnson (1970, p, pv) acknowledged that their approach to sex therapy was nativist and ideological and not applicable to the general population but defended their research on the basis that their approach to treating sexual problems was new and ground-breaking. In 1983 William Masters in an address to the World Congress of Sexology stated that his studies were conducted in 1960s America and his research tools were state of the art at the time (Masters et al, 1983).

In the 1970s two academic theories of sexuality emerged. In the world of social sciences a social constructionist perspective highlighted the importance of political, economic and social determinants in contributing to a fulfilling sexual life, with learning and education being identified as the keys to sexual satisfaction. In psychology and medicine a reductionist perspective emphasised that sexual satisfaction was dependant on evolutionary patterns of sexual motivation, sexual attraction, and sexual conduct (Weeks, 1985, p 324). Masters and Johnson (1970) contributed to the reductionist theory by defining the sexual response and labeling sexual problems using medical terminology (Conrad, 2007, p 5). Although Masters and Johnson were part of the process that medicalised ED and its treatment medicalisation of ED has evolved and ED is now considered to be a disease that is specific only to men. On page 2 of "Human Sexual Inadequacy" (1970) it states that "there is no such thing as an uninvolved partner in any marriage in which there is some form of sexual inadequacy" yet current trends in prescribing of ED treatment disregard this opinion.

In 1982, Virag, influenced by the work of Michal, Kramer and Pospichal (1977)

published an article in the *Lancet*, on the vaso-active properties of papaverine hydrochloride when administered by intracavernosal or intrapenile injection. These data pioneered a new era of medical treatment for ED. Research into injection therapies focussed on the physiology of penile tumescence and disregarded the psychological and social factors associated with ED (Brindley, 1983; Virag et al, 1984; Buvat et al, 1986; Stackl, Hassun and Marberger, 1988; Buvat et al, 1991). The relationship between erectile function, sexual drive, sexual desire, ejaculation and orgasmic sensation was not considered in these studies and partners of men with ED were not included (Brindley, 1983; Buvat et al, 1986; Stackl, Hassun and Marberger, 1988; Buvat et al, 1991). In response to the introduction of intracavernosal alprostadil the National Institute of Health (NIH, 1993) published a best practise consensus document on assessment and treatment of ED (NIH, 1993). These data described erectile function in isolation from the other aspects of the male sexual response and failed to consider relationship issues.

Papaverine was not licensed to treat ED but was widely prescribed throughout the 1980s (British National Formulary, 2009, p 458). The success of papaverine inspired testing of other chemical agents by intracavernosal injection (Brindley, 1983) and in 1994, following research into the use of intracavernosal prostaglandins; intracavernosal alprostadil (prostaglandin E1) became the first licensed treatment for ED (Brindley, 1983; Porst, 1996; British National Formulary, 2009, p, 456-457). The introduction of intracavernosal alprostadil increased awareness of ED and provided an alternative to vacuum tumescence therapy and penile implant surgery (Goldstein and Lue, 1993). Although successful attempts were made to integrate treatment for ED by using injection therapy in conjunction with psychosexual counselling interventions (Colson, 1995; Rosen and Lieblum, 1995; Sarwer and Durlak, 1997) these data were considered irrelevant in studies that focussed solely on the vaso-active properties of alprostadil when

administered by intracavernosal injection (Buvat et al, 1991; Althof et al, 1992; Porst, 1997a, p 175-192).

Pharmaceutical companies financed research in the hope of developing a user friendly treatment for ED with superior characteristics in relation to safety, efficacy and tolerability when compared to alprostadil and papaverine injections (McMahon, 1991, Goldstein and Lue, 1993; Porst and Biedermann 1993; Linet and Neff, 1994; Porst et al, 1994; Linet and Ogrinc, 1996). Constructionist theorists joined forces with psychosexual therapists in objecting to medical therapy and stated their case by outlining the potential problems associated with an extreme reductionist approach to assessment and treatment of ED (Tiefer, 1986; Bancroft, 1989, p 441- 443; Colson, 1995). In the search for a user-friendly treatment the pharmaceutical industry provided funding for myriad studies which ultimately influenced medical hegemony in terms of labelling ED as a male medical problem (Lexchin, 2006) and research into efficacy of intracavernosal prostaglandin E1 (alprostadil) continued to assess treatment success that was solely based on measurement of penile rigidity (Brindley, 1983; Buvat et al, 1986; Buvat et al, 1991; Althof et al, 1992; Porst, 1996; Porst, 1997a, p 175-192).

Intraurethral alprostadil or Medicated Urethral System for Erection (MUSE) was introduced in 1996 as an alternative to intracavernosal injections (Anastasiadis et al, 2002). Measuring efficacy of intraurethral alprostadil included observing the patient's response following administration of MUSE in the clinicians "office" (Porst, 1997b; Padma-Nathan et al, 1997; Fulgham et al, 1998). In these studies efficacy was reported to be as low as 30% (Porst, 1997b; Padma-Nathan et al, 1997; Fulgham et al, 1998). Observing the patient's response in "the office" was not considered to be a significant variable in terms of treatment success (Porst, 1997b; Padma-Nathan et al, 1997; Fulgham

et al, 1998).

Cessation of intracavernosal and intraurethral alprostadil was found to be common and was attributed to poor efficacy, penile pain and reluctance among men to continue using invasive therapies (Padma-Nathan et al, 1994; Porst 1997a, p 175-192; Padma-Nathan et al, 1997; Werthman and Raifer, 1997; Porst 1997b; Fulgham et al, 1998; Costabile, 1999). However feedback from women on their partner's use of intracavernosal alprostadil suggested that injection therapy was not acceptable to some women due to the prosthetic nature of the treatment and the erectile response (Althof et al, 1992). This information suggests that women (partners of men with ED) were not considered at assessment and were expected to adapt to their partner's use of penile injections prior to sexual activity regardless of their circumstances.

Following administration of intracavernosal alprostadil penile tumescence is not dependant on sexual stimulation which devalues the importance of intimacy and sexual interaction (Althof et al, 1992; Son et al, 2004a). Althof et al, (1992) reported that intracavernosal alprostadil injections "improved sexual function in women" by restoring their partner's erectile response although the opinions of women in this study were influenced by men. Women were not asked to describe "the problem" and no long term follow up data were obtained from these women to assess whether "improvement" had been maintained (Althof et al, 1992). Outcome measures were confined to quantitative psychometric assessment at baseline and endpoint and there was no reference, in this study, to sexual expression in terms of emotion or intimacy (Althof et al, 1992). Intracavernosal alprostadil may have facilitated sexual intercourse for these couples but "facilitation" might not appeal to some women, particularly in the absence of intimacy (Althof et al, 1992). These data did not consider the dynamics of the relationship and

neglected that ED might have caused significant disruption to the relationship prior to treatment being prescribed.

In the 1990s little was known about the influence of female sexual problems on male sexual function and women were not asked about the effect of the menopause on their sexual function prior to their partners being prescribed penile injections or intraurethral alprostadil pellets. Studies that combined the concepts of Masters and Johnson's (1970) sex therapy with new medical treatments were promising in terms of maximising treatment success (Rosen and Leiblum, 1995; Lottman et al, 1998) although these data seemed to get lost among the proliferation of research that focussed on restoration of erectile function and treatment success according to IIEF baseline to endpoint scores (Goldstein et al, 1998; Padma-Nathan and Giuliano, 2001; Stuckey et al, 2003; Porst et al, 2003; Montorsi et al, 2004).

### **Epidemiology of ED**

The first large scale epidemiological study of ED was published in 1994 and considered ED in terms of severity and its association with the age (Feldman et al, 1994). The Massachusetts Male Ageing Study (MAMAS) surveyed cohort samples of men from 11 towns and cities near Boston (Feldman et al, 1994). Information was obtained from 1,709 men via interviews and pre-set questionnaires that asked men about their erectile function, socio-demographic status, psychological health, physical health and medications and lifestyle. The MAMAS estimated the prevalence of ED in the United States of America at between 18-30 million and highlighted that the incidence of ED increased with age (Feldman et al, 1994). The MAMAS continues to be the most widely used citation on the incidence of ED (Goldstein 2004; Kantor et al, 2002; Korenman 2004) and was used to calculate the incidence of ED on a global scale (Feldman et al, 1994). Results of the

MAMAS emphasised that ED was underestimated in terms of its prevalence.

On close scrutiny of the research methods that were used in the MAMAS it is reasonable to suggest that its conclusions were inaccurate. The population sample was split into two groups: a larger group consisting of men randomly selected from towns and cities and a smaller group of men that presented at a urology clinic. Both groups of men were asked the same questions although only the smaller group of men were asked to complete a self-rating scale to measure their erectile function. Feedback from the smaller population sample was applied to the larger sample and a combined incidence of ED was calculated and applied to the total population. It is reasonable to suggest that ED would have been more prevalent in the smaller population sample as this group of men were recruited from a urology clinic. Although other studies support the results of the MAMAS (Braun et al, 2000; Selvin, Burnett and Platz, 2007) its conclusions have also been rejected (Burls, Clark and Gold, 1998; Laumann, Paik and Rosen, 1999; Blanker et al, 2001). The MAMAS did not ask men if they considered ED to be problematic (Feldman et al, 1994). Erectile dysfunction was categorised in the MAMAS as mild, moderate and severe and no information was obtained from partners of that reported ED.

The MAMAS focussed on one aspect of the male sexual response although ED often co-exists with other sexual problems (Rust et al, 1986; Bejin, 1999). Concomitant sexual problems may be influenced by multi-factorial aetiology, complex psychology or a single underlying condition such as androgen deficiency, which is known to impact on all aspects of male sexual function (Bancroft, 1989, p 288). Although deterioration in erectile function is common and is associated with the ageing process (Laumann, Paik and Rosen, 1999; Braun et al, 2000; Kubin, Wagner, Fugl-Meyer, 2003) there is ambiguity in terms of defining “normal” and “abnormal” decline in the erectile response

of the ageing male (Ansong et al, 2000; Shiri et al, 2003). Self-diagnosis of ED may be influenced by the power of suggestion. The high prevalence of concomitant sexual problems emphasises the importance of accurate assessment of men that present with ED. Treating ED in men with concomitant sexual disorders may not restore sexual function (Ventegodt, 1998; Bejin, 1999; Simons and Carey, 2001; Fugl-Meyer and Fugl-Meyer, 2002).

### **Aetiology of ED**

Masters and Johnson (1970) considered sexual problems to be influenced by many factors although in the 1960s the relationship between organic disease and sexual dysfunction was poorly understood. Masters and Johnson (1970) focussed on treatment for psychological inhibition of sexual function including performance anxiety, fear of failure, guilt and other psychological barriers. Psychological inhibition of erectile function is often difficult to treat and it was recognised by Masters and Johnson (1970) that psychological influences on sexual problems often stemmed from relationship issues. Other studies have reported on the severity of sexual problems that have been caused by psychological aetiology (Riley and Riley, 1999; Bancroft et al., 2005; Althof et al, 2005).

Between the late 1980s and mid 1990s specialist diagnostic tests to measure penile blood flow were introduced and new knowledge was published on the physiology of erectile function (Porst and Biederman, 1993). These data and other studies suggested that organic aetiology was evident in 80% of men that presented with ED (Porst and Biedermann, 1993; Wegner et al, 1995; Foreman and Doherty, 1993; Saenz de Tejada and Moncada 1997; Melman and Gingell, 1999). Organic ED is influenced by vascular insufficiency and neurological impairment, surgical and non surgical trauma, drugs, endocrine abnormalities, pain and structural disorders such as congenital filling defects,

penile fracture and Peyronie's disease (Bancroft, 1989, p 376-380; Porst, 1996; Eardley and Sethia, 2003; Ralph and Minhas, 2004).

Following the introduction of sildenafil citrate (Viagra) medical insurance providers in America sought clarity on the definition of ED in order to define policy criteria on reimbursement of erectogenic treatment costs (American Psychiatric Association of Diagnostic and Statistical Manual of Mental Disorders IV, 2000; Tiefer, 2004, p 304). However classifying ED in terms of disease taxonomy was difficult as it is often a symptom of underlying pathology and is associated with various co-morbidities including depression and mental illness (Seftel, Sun and Swindle, 2004; Rosen et al, 2004). Psychological problems may influence ED in the presence of multiple organic co-morbidities and medical therapy is unlikely to solve psychological issues that require thorough assessment and couple counselling (Melnik, Soares and Nasello, 2008).

Relationship issues that contribute to sexual problems may be complex. For example ED may manifest in men whose partners fail to reach orgasm although expectation of the orgasmic experience may be inaccurate. Research has shown that women's descriptions of orgasmic sensation vary considerably (Ellis, 1953; Bancroft, 1989, p 373; Nicolson and Burr, 2003). Sex may be a challenge if sexual goals include unrealistic ideas about sexual pleasure and sexual satisfaction. If sex becomes challenging it is likely to be associated with anxiety, which ultimately results in failure (Kaplan, 1988; Rosen, 2001; Hedon, 2003; Binik and Meana, 2009).

### **Treatment of ED post Viagra**

There was no immediate change in the approach to studies of treatment for ED following

the launch of sildenafil citrate (Viagra). Research continued to focus on “hardness” and “duration” of the erectile response by using mean analysis of IIEF baseline to end-point scores (Boolell et al, 1996; Price et al, 1998; Goldstein et al, 1998; Morales et al, 1998; Padma-Nathan et al, 1997; Ballard et al, 1998; Rendell et al, 1999; Conti, Pepine and Sweeney, 1999; Dinsmore et al, 1999). Assessment of ED from a couple’s perspective was largely neglected and research outcomes in terms of opinion on treatment focussed on feedback from men (Boolel et al, 1998; Goldstein et al, 1998; Morales et al, 1998; Ballard et al, 1998; Padma-Nathan et al, 1999; Rendell et al, 1999; Conti, Pepine and Sweeney, 1999; Dinsmore et al, 1999).

Sublingual apomorphine (Uprima) was licensed to treat ED soon after the launch of sildenafil citrate (Viagra) and its efficacy was assessed by analysing IIEF scores pre and post treatment (Padma-Nathan et al, 1999; Altwein and Keuler, 2001; Pryor, 2002; Kell, Dean and Ralph, 2002; Brock, 2002; Mulhall, 2002). Apomorphine (Uprima), a sublingual dopamine agonist, enhanced the central dopaminergic action associated with the erectile response and although the concept was based on promising theoretical data (Heaton, 2000; Morales and Heaton, 2002; Mulhall, 2002) poor efficacy and side effects including yawning and vomiting ultimately led to its withdrawal in 2006 (Altwein and Keuler, 2001; Simmons, 2010).

In 2003 two new phosphodiesterase type 5 (PDE5) inhibitors, tadalafil (Cialis) and vardenafil (Levitra) were licensed to treat ED and created a competitive market, as reported efficacy of both drugs was similar or superior when compared to sildenafil citrate (Viagra) (Saenz de Tejada et al, 2002; Brock et al, 2002; Porst et al, 2003; Corbin et al, 2004; Hammadeh et al, 2004; Fisher et al 2005b). Tadalafil (Cialis) has a longer duration of action than both sildenafil citrate (Viagra) and vardenafil (Levitra) and

reports have suggested that it has overtaken sales of sildenafil citrate (Viagra) in some market sectors (Medical News Today, 2005; Kaminov, 2010). Vardenafil (Levitra) is a short acting drug similar to sildenafil citrate (Viagra) but with greater affinity to inhibition of PDE type 5 (there are 11 types of phosphodiesterase) which is thought to reduce the incidence and severity of side effects such as facial flushing, photosensitivity and gastric upset (Corbin et al, 2004; Makhlof, Kshirsagar and Niederberger, 2006).

New treatments for ED are continuing to be assessed including another oral PDE5 inhibitor (Avanafil) and a topical alprostadil gel (Topiglan) which although is not a new concept has never been licensed to treat ED (Steidle et al, 2002; Padma-Nathan et al, 2003; Sandner et al, 2007). Since the introduction of Cialis and Vardenafil marketing of PDE5 inhibitors has been targeted at a wider audience influencing opinion that recreational use of erectogenic treatment is being promoted by the pharmaceutical industry (Gresser and Gleiter, 2002; Govier et al, 2003; Lexchin, 2006; Asberg and Johnson).

Although women or female partners of men with ED have been included in recent studies of ED treatment subjective feedback from these studies was restricted by asking women to complete questionnaires (Seftel et al, 2009; Chew, et al, 2009; Chevret-Measson, 2009). Other studies have reported on the impact of ED from a woman's perspective although the opinions expressed in these studies relied on feedback from men that were asked about the impact of ED treatment on their partners (Althof et al 2006; King et al, 2007; Farca et al 2008; Cappelleri et al, 2008). Excluding partners of men with ED from assessment and treatment decisions is likely to have a negative influence on treatment success and may influence treatment cessation. Cessation of erectogenic treatment is common and similar cessation rates apply to all of the medical therapies including oral

medication, vacuum tumescence therapy and intracavernosal injections (Lewis and Worthington 1997; Son et al, 2004b; Jiann et al, 2006; Cimen et al, 2009; Hatzimouratidis and Hatzichristou, 2009). “Relationship issues” were listed in these studies as a potential influence on treatment cessation although no information on the couple’s relationship was obtained from men and their partners. Feedback from men was collected by telephone survey or by psychometric assessment (Son et al, 2004; Jiann et al, 2006; Cimen et al, 2009; Hatzimouratidis and Hatzichristou, 2009). It is reasonable to suggest that cessation of ED treatment is likely to occur if partners of men with ED experience sexual pain or lack sexual desire, however there are no qualitative studies that have assessed sexual function from a couple’s perspective prior to initiating ED treatment. It has been found that partners of men with penile curvature or Peyronie’s disease experience sexual pain and discrepancy in sexual drive between men with ED and their partners is known to cause conflict therefore if incompatibility exists but is not identified ED treatment may not rectify the problem (Keesling, 2006, p 209; Davies, Katz and Jackson, 1999).

Chevret-Measson et al, (2004) recruited 712 men with ED and their partners and asked them to provide feedback on their sexual function via psychometric assessment questionnaires. The study was designed to gain insight into the incidence of sexual problems in partners of men with ED and to assess whether ED was more prevalent in partners of women with sexual problems. The Index of Sexual Life (ISL) revealed that ED was more common in partners of women that reported poor sexual drive than in partners of women that considered their sexual drive to be “normal”. Although lack of sexual interest among partners of men with ED may be a contributory factor in terms of influencing ED it is reasonable to suggest that lack of sexual drive in women may be more common in women whose partners experience ED. Women with lower levels of

sexual drive in this study were, on average, 10 years older than women with “normal” levels of sexual drive and therefore were more likely to have been menopausal. The menopause is known to reduce sexual drive (The North American Menopause Society, 2005). It is also interesting to note that 36.4% of the women that were considered to have poor sexual drive according to feedback from the ISL reported no sexual problems. This study suggests that relying on interpretation of feedback from psychometric assessment may lead to inaccurate conclusions. Psychometric assessment of sexual function does not allow for clarification of conflicting responses.

Chevret-Measson et al (2004) recruited couple samples and used quantitative methods to collect and analyse data. Feedback from both partners was compared and potential relationships between sexual deficit in women and ED were considered although no information was obtained from the couple on the impact of ED. Defining “normal” in terms of sexual function is difficult as “normal” sexual activity may be unique to each couple therefore deviation from “normal” may also be unique (Sheiber, 2008). The importance of assessing ED from a couple’s perspective was emphasised in the feedback obtained from psychometric assessment and highlighted that questionnaires may not identify the nature of the problem from the couple’s perspective. Men in this study considered ED to be problematic although over one third of their partners reported that they experienced no sexual problems.

Treatment preference of men with ED and their partners has been assessed by various crossover studies and head to head comparisons of sildenafil citrate (Viagra), tadalafil (Cialis) and vardenafil (Levitra) (Conaglen and Conaglen, 2008a; Rubio-Aurioles et al, 2009; Kaminetsky et al, 2009; Althof et al, 2010). None of these studies used qualitative research methods to obtain subjective opinion from couples on treatment preference.

Brock et al (2007) assessed treatment preference of men with ED and their partners by comparing feedback from couples on their experience of using sildenafil citrate (Viagra) and tadalafil (Cialis). Both partners completed questionnaires (the Erectile Dysfunction Inventory of Treatment Satisfaction) (EDITS) at baseline, at crossover (4 weeks) and at end-point (12 weeks). Brock et al (2007) reported that couples preferred tadalafil (Cialis) although treatment preference of women in this study was not thoroughly assessed. At enrolment 2425 men and their partners agreed to participate in this study and approximately 98% of these men completed questionnaires on treatment preference at baseline, 4 weeks and 12 weeks. Questionnaires at 12 weeks were completed by only 295 women therefore no valid conclusions on treatment preference of the women in this study can be made from these data. Brock et al (2007) did not provide information on why so many women failed to complete the study.

In 2004 Fisher et al published a study that looked at the “treatment seeking characteristics of men with ED”. Findings from this study were limited by neglecting the influence of partners on treatment seeking behaviour of men with ED although 5 years later Fisher et al (2009) addressed this issue in a study that specifically looked at the “association of female partner characteristics with male partner ED treatment seeking behaviour”. The women that participated in this study were partners of men that Fisher et al (2004) recruited to provide information on treatment seeking behaviour. Although Fisher et al (2009) may have considered partners to be relevant in terms of influencing treatment seeking behaviour of men with ED women were asked to provide retrospective feedback via postal questionnaire on their circumstances after 5 years had elapse whereas their partners provided feedback on their predicament when living with ED and its consequences. Data collection by postal questionnaires has been criticised due to the

large numbers of non-respondents (Apfelbaum, 1982).

Although in recent years research into ED and its treatment has become more considerate of partner issues (Brock et al, 2007, Conaglen and Conaglen, 2008a; Rubio-Aurioles et al, 2009; Kaminetsky et al, 2009; Fisher et al, 2009; Althof et al, 2010) recent studies have also continued to measure treatment success on the basis of the organic response (Mulhall et al, 2008; Kaminetsky et al, 2009; Claes et al, 2010). A scoring system to grade the erectile response, similar to the outcome measures that were used in the 1980s and 1990s to assess efficacy of intracavernosal injection therapies, has been recommended as an adjunctive aid to determining treatment success (Stackl, Hassun and Marberger, 1988; Porst 1997b; Padma-Nathan, 1997; Kaminetsky et al, 2009; Claes et al, 2010). It has been suggested that the patient's doctor is best placed to judge treatment success in terms of penile tumescence (Kaminetsky et al, 2009; Claes et al, 2010) although in a study by Potts et al (2004) a group of women whose partners experienced ED identified that they openly communicated their sexual needs by judging Viagra in terms of erection hardness and sexual pleasure. These women were expressive and specific in terms of communicating their sexual needs to their partners prior to and post treatment and did not hesitate to inform their partners when their sexual needs were not being met. Promoting treatment success in terms of erection hardness, however, may influence unrealistic expectations of ED treatment and ultimately contribute to poor treatment outcomes (Mulhall et al, 2008; Kaminetsky et al, 2009; Claes et al, 2010).

### **Psychometric assessment of the impact of ED and efficacy of erectogenic treatment**

In an attempt to gain insight into the impact of ED treatment on “relationship satisfaction”

Rosen et al (2006) used a variety of validated psychometric questionnaires including the Dyadic Adjustment Scale (DAS), the Depression Anxiety Stress Scale (DASS), the Sexual Inhibition Scale/Sexual Excitation Scale (SIS/SES), the Erectile Dysfunction Inventory of Treatment Satisfaction (EDITS) and the Brief Index of Sexual Function for Women (BISF-W). Sixty-nine men with ED and their partners participated in this study and provided feedback via psychometric assessment prior to and post treatment with sildenafil citrate (Viagra). The IIEF and the Erectile Dysfunction Inventory of Treatment Satisfaction (EDITS) was used to measure male sexual function/satisfaction and women completed the Brief Index of Sexual Function for Women (BISF-W) and the Sexual Inhibition Scale/Sexual Excitation Scale (SIS/SES). Feedback from the BISF-W highlighted that 70% of women experienced compromise in their sexual function including difficulty reaching orgasm (31%), lack of vaginal lubrication (19%), vaginal tightness (16%) and dyspareunia (8.8%). Psychometric assessment did not clarify the significance of these results. Dyspareunia or sexual pain is likely to disrupt sexual activity and if vaginal dryness and vaginal tightness caused dyspareunia then approximately 42% of women in this study experienced pain during sexual activity. Difficulty associated with orgasm was reported to be the most common sexual dysfunction among women in this study (31%) although orgasm is perhaps the most misunderstood aspect of the human sexual response (Ellis, 1953; Bancroft, 1989, p. 291).

Information from this study on the impact of ED and its treatment on relationship satisfaction was confusing. Scores on the Dyadic Adjustment Scale (DAS) suggested that couples were satisfied with their relationship prior to and post ED treatment therefore according to these data ED had no effect on the relationship. However both partners recorded improvement in IIEF, EDITS and BISF (sexual satisfaction) baseline to end-point scores. Another study that assessed the impact of ED and its treatment on men and their partners found that the DAS produced similar results (Hundertmark et al, 2007)

although other studies have found that ED disrupted relationships between men and their partners (Althof et al 2006, King et al, 2007, Farca et al, 2008, Cappelleri et al, 2008). Rosen et al (2006) suggested that sexual function improved in both partners if men responded to ED treatment although this information may be misleading as less than 50% of women in this study provided feedback on treatment success (Rosen et al, 2006). Psychometric questionnaires have been used in other studies to identify sexual problems in partners of men with ED (Greenstein et al, 2006; Heiman et al, 2007). Although feedback from questionnaires in these studies suggested that sexual problems were common in partners of men with ED change in sexual function among these women was not identified as being problematic. It has been found that women have reported change in their sexual function without considering the changes they have experienced to be problematic (Rutherford and Collier, 2005).

Quantitative studies have looked at the impact of ED on the quality of life of men (Porst 1997b, Seidman et al, 2001, MacDonagh, Porter and Ewings, 2002; Meyer et al 2003) and couples (MacDonagh et al, 2004; Sand et al, 2008) but subjective accounts on the impact of ED from both partners have not been obtained. It is thought to be imperative that research into the impact of chronic disease on couples considers the opinions and experiences of both partners (Bodenmann, 2005). It is therefore reasonable to suggest that conclusions from studies on the impact of ED and its treatment may be inaccurate if partners of men with ED have not been given the opportunity to express their opinion. Although the literature review revealed studies that produced information on the impact of ED on men and women these studies did not include couple samples and insight into the couple's predicament was limited by asking women and their partners specific questions from pre set questionnaires (Paige et al, 2001; Fergus, Gray and Fitch, 2002; Latini et al, 2002; Latini et al, 2003; Tomlinson and Wright, 2004; Fisher et al, 2005b;

Rosen et al, 2006).

Qualitative research has produced valuable insight into the opinions of women on ED treatment (Vares et al, 2007; Conaglen and Conaglen, 2008a). These studies did not obtain feedback on the impact of ED from partners of these women. Women were relied upon to provide feedback on the severity of their partner's ED, information on treatment and opinion on treatment success. Most of the women in these studies either accepted treatment for ED or expressed that ED treatment influenced improvement in the quality of their lives. None of these women reported experiencing sexual pain despite the prevalence of sexual pain in partners of men with ED in other studies (Chevret-Measson, 2004; Rosen et al, 2006). Conaglen and Conaglen (2008b) looked at the impact of ED on women (n = 51) in a study that recruited partners of men with ED from newspaper advertisements. Women participated in semi-structured interviews and feedback from interviews identified that these women were concerned about the prospect of ED being a sign of underlying disease. It is unknown if the women in this study represented partners of men with severe, moderate or mild ED and opinion on the impact of ED and its treatment was not considered from the couple's perspective.

McCabe et al, (2010) conducted a qualitative study to obtain information on women's motivation to seek ED treatment. Feedback from semi-structured interviews revealed that women in this study actively sought ED treatment. Partners of women were not included in this study. Subjective feedback from women provided valuable insight into ED from a woman's perspective although the data was weak in terms of communicating how couples adjust to living with ED. Women may not be motivated to seek treatment for ED for various reasons including opinion that ED is not evident or affecting sexual pleasure (Rosen et al, 2006). It is reasonable to suggest that disagreement between women and

their partners on whether a problem exists may influence conflict, which may affect opinion on treatment and treatment success.

### **Measuring treatment success**

Masters and Johnson's (1970) preoccupation with measuring treatment outcomes in terms of successful coitus relates to IIEF assessment of ED and erectogenic treatment (Rosen et al, 1997; Rosen et al, 2006). Although Masters and Johnson (1970) did not prescribe drug therapies for sexual problems their outcome measures included parameters that considered the erectile response in terms of "hardness" and "duration". There is limited reference to subjective analysis of sexual problems by Masters and Johnson (1970) and although reported outcomes suggest that only 5% of "clients" experienced recurrence of sexual problems after 5 years more than half of the original population sample failed to attend follow up interviews.

Research into papaverine and other chemical agents such as phentolamine and prostaglandin E1 focussed on the erectile response, the incidence of pain and the propensity for the drug to induce priapism or prolonged erection (Keogh et al, 1988; Buvat et al, 1989; Porst and Biederman, 1993; Linet and Neff, 1994). Efficacy of intracavernosal moxisylyte has been assessed following administration "in the office" and at home (Buvat et al, 1989). Feedback from this study revealed that 35% of the population sample (n=91) responded to moxisylyte "at home" but failed to respond "in the office" (Buvat et al, 1989). Similar results were reported in another study (Colson, 1995). Feedback from studies of intracavernosal alprostadil included limited information on assessment of ED and the rationale behind treatment (MacMahon, 1991; Porst and Biederman, 1993; Linet and Neff, 1994; Linet and Ogrinc, 1996; Porst, 1996; Porst et al, 1998). Other studies looked at efficacy and safety of other vaso-active compounds when

administered by intracavernosal injection and although often used in combination with alprostadil none of these preparations were licensed to treat ED (MacMahon, 1991; Porst and Biederman, 1993; Linet and Neff, 1994; Linet and Ogrinc, 1996; Porst, 1996; Porst et al, 1998). It has been reported that the rate of cessation among men using intracavernosal alprostadil after 1 year is approximately 30% (Linet, 1994; Porst, 1996; Porst 1997a, p 185-189). Feedback from these studies suggested that alprostadil injections were discontinued due to “restoration of spontaneous erections, debilitating disease, patient’s lack of fitness, poor efficacy and partner problems” (Linet, 1994; Porst, 1996; Porst 1997a, p 185-189). The nature of “partner problems” was not discussed in any of these studies.

Studies that compared efficacy of intraurethral and intracavernosal alprostadil focussed on “hardness” and “duration” of the erectile response (Porst, 1997a, p 186-189; Porst 1997b; Padma-Nathan, 1997). In a comparative study by Porst (1997b) efficacy of intraurethral and intracavernosal alprostadil was assessed by using “subjective” outcome measurements, which included a basic scoring system that was used to grade penile tumescence pre and post administration of alprostadil. Erection scores ranged from 1-5 with categories 4 (full tumescence, partial rigidity) and 5 (full rigid erection) indicating treatment success. Intracavernosal alprostadil was found to be more successful in terms of influencing penile rigidity. Other methods of defining treatment success included measurement of systolic peak flow velocities and end-diastolic flow velocities in the deep penile arteries (Porst 1997b). Dyadic assessment of sexual satisfaction was not considered in this study and other studies that compared efficacy on intraurethral and intracavernosal alprostadil (Porst, 1997a p 186-189; Porst, 1997b; Padma-Nathan et al, 1997).

Measurement of systolic peak flow velocities and end-diastolic flow velocities does not consider the couple's perspective on defining treatment success and neglects the social consequences of ED and the subjective nature of sexual expression (Porst, 1997a, p 175-192; Porst 1997b, Padma-Nathan et al, 1997). Without obtaining information from men and their partners on the impact of ED erectogenic treatment may be prescribed to solve a problem that doesn't exist. Treatment success in terms of sexual fulfilment and sexual satisfaction is likely to involve intimacy and interpersonal qualities that are influenced by unique aspects of a couple's relationship.

Although Masters and Johnson (1970) were accused of medicalising sex, the introduction of drug therapies for ED established a distinct relationship between medicine and sex. Sexual dysfunction became part of a list of age-related conditions that were common and considered by drug companies to be potentially viable target areas for the development of new drug treatments (Conrad, 2007, p 5)

### **Medicalisation of sex**

The first studies to conceptualise the process of medicalisation were published in the late 1960s and early 1970s (Pitts, 1968; Friedson, 1970; Zola, 1972). Medicalisation is a process that begins with “a problem that is defined in medical terms, described using medical language and understood through the adoption of a medical framework or treated with a medical intervention” (Conrad, 2007, p 5). Part of the process of medicalising male sexual function was changing the term “impotence” to erectile dysfunction in order to be more specific in terms of medical diagnosis. Scientific investigations into the aetiology of ED (Stief et al, 1991; Sattar, Merckx and Wespes, 1996) and the introduction

of erectogenic drug treatment completed the process (Stackl, Hassun and Marberger, 1988; Porst et al, 1998). Conrad's (2007, p 5) description of medicalising human deviation includes the identification of "problems" that might be treatable with existing drug therapies and identifying new drug therapies that might be used to treat common or existing "problems". Treatment of ED applies to these criteria as sildenafil citrate (Viagra) was designed to treat angina but was found during clinical trials to improve erectile function (Ghofrani, Osterloh and Grimminger et al, 2006) and relates to the concept of using sildenafil citrate to treat sexual problems in women (Tiefer, 1996; Tiefer, 2001).

Although the term "medicalisation" implies that the process is always driven by the medical profession, it is often more complex. Alcoholism was medicalised in response to a social movement (Alcoholics Anonymous) which campaigned for years to have alcohol addiction recognised as an illness prior to the medical profession classifying alcoholism as a disease (Appleton, 1995). Other categories of human deviance that have been medicalised include eating disorders, mental problems, opiate addiction, gender differences and learning disabilities (Conrad, 2007, p 6). The process of medicalisation has been influenced by the defining of specific criteria for medical insurance purposes, the discovery of new aetiologies, the introduction of new drugs and opinion and support of the medical profession (Moynihan and Henry, 2006; Conrad 2007, p 6).

Sex was considered in medical terms long before chemical compounds were introduced to treat ED (Money, 1887, p 421). Desire to be "normal" in terms of sexual appearance, sexual function and sexual performance is an important aspect of human psychological well-being despite "normal sex" being a product of medical or surgical intervention (Goodman et al, 2000). Young women are increasingly requesting surgical correction of asymmetrical labia (labiaplasty) for aesthetic reasons regardless that asymmetrical labia

are not atypical (Braun, 2005; Goodman et al, 2010). The frequency of prescribing testosterone replacement is increasing and new treatments for ED continue to be developed (Clayton, 2010; Iacono et al, 2010). Marketing campaigns for “lifestyle drugs” promote the notion that the ageing process is reversible (Gullette, 1997, p 231; Mamo and Fishman, 2001; Sheiber, 2008). Deterioration in sexual function associated with age has become unacceptable (see Marshall B. “Hard Science”: Gendered Constructions of Sexual Dysfunction in the ‘Viagra Age’, 2002). When sildenafil citrate (Viagra) was identified as a potential treatment for ED the MAMAS was identifying the prevalence of ED and the IIEF was in the process of defining new parameters of “normal” erectile function (Feldman et al, 1994; Rosen et al, 1997; Rosen, Padma-Nathan and Goldstein, 1999). Viagra influenced momentum in the process of advancing the concept that ED was a medical problem. The media, fuelled by the novelty of a new “sex drug” informed the world’s population that the introduction of an oral treatment for ED was imminent.

Medicalisation of human sexuality was almost inevitable. Confusion associated with “normal” sexual function invited medical authority to define sexual norms. Drug therapies provided an avenue for people to conform to sexual ideologies that had been promoted by the companies that produced drug to treat ED. As drug patents expire and new drugs are developed the lines that define the parameters of human deviation will become narrower and will continue to be driven by potential profit (Berger, 1998; Katz and Marshall, 2004; Lexchin, 2006). Media obsession with Viagra included live TV “Viagra experiments” that portrayed ED in comedic terms and promoted Viagra as a recreational drug (Turner, 2007). Such was the controversy associated with these “experiments” that the Daily Mail labelled the stunt as “the tawdriest hour of British TV ever” (Turner, 2007). Although sex is often considered to be a recreational activity ED can cause distress and lead to depression (Seftel, Sun and Swindle, 2004; Rosen et al,

2004) and has been linked to other conditions such as hypertension, hyperlipidaemia and diabetes (Seftel, Sun and Swindle, 2004; Rosen et al, 2004). In the “Viagra experiments” men with ED and their partners used the drug in a nearby hotel room and reported on their experience to a live television audience. The prospect of feeding back details to the nation on such an intimate experience possibly affected the results of the “experiment” (Turner, 2007).

It has been reported that medicalisation of men’s lives is relatively new in comparison with medicalisation of women’s lives (Reissman, 1983; Friedan, 1993; Lock, 1993). There are many articles on the medicalisation of women’s lives (Brumberg, 1988; Bell, 1990; Bransen, 1992; Figert, 1995; Armstrong, 1999; Oinas, 2001; Johanson, Newburn and McFarlane, 2002) although few articles discuss medicalisation of female sexual function. It has been suggested that men become “invisible” as they get older and their role in society becomes less obvious whereas women are thought to be more aware of the physical signs of ageing and more likely to use lifestyle drugs in an attempt to delay the ageing process (Riessman, 1983; Thompson, 1994). Medicalisation of human sexual function did not adhere to this trend. Drugs to improve erectile function were welcomed by men whereas women contested the pharmaceutical industry’s opinion on female sexual function (Friedan, 1993; Tiefer and Tavris, 1999; Tiefer and Giami, 2002). Women’s concerns about medicalising male sexual function were largely ignored (Altwein and Keuler, 2001; Tiefer, 1996; Tiefer, 2000). Studies that promoted medical treatment for sexual problems were mostly driven and conducted by men (Padma-Nathan et al, 1999; Altwein and Keuler, 2001; Tiefer, 2000; Pryor, 2002; Kell, Dean and Ralph, 2002).

Profit from Viagra sales confirmed beyond doubt that male sexual function is a valuable

commodity (Lexchin, 2006). The prospect of Viagra for women was considered by the American media soon after Viagra was licensed to treat ED (Mayor, 2004). Pfizer acknowledged the potential for financial gain associated with drug treatment for sexual problems in women although identifying a problem in women for Viagra to treat was difficult (Tiefer and Tavris, 1999; Mayor, 2004). Approximately 3,000 women participated in several large scale, placebo controlled studies on the effect of sildenafil citrate on “female sexual arousal disorder” although feedback on treatment benefit was inconclusive (Mayor, 2004).

In May 1997 at a conference in Cape Cod diagnostic criteria for female sexual dysfunction (FSD) was considered by a group of leading urologists and specialists in the field of sexual medicine. The issues associated with defining diagnostic criteria for FSD were addressed and articles on presentations and discussions about FSD were published in the International Journal of Impotence Research (Rosen and O'Leary, 1997). Although further attempts have been made to separate female sexual health and medical disorder disagreement on the definition of female sexual dysfunction persists (Basson et al, 2004; Giraldi, 2010). In 2000 the “New View Campaign” was formed in order to dispel myths about female sexual function and increase awareness of female sexual problems (New View, 2000; New View, 2002). The New View Campaign rather than dismissing sexual problems in women challenged the medical approach to solving female sexual problems and promoted a politically sensitive, scientific and social perspective of female sexuality and and sexual function and highlighted that attempts to define “normal” sexual function in women via diagnostic criteria was insensitive and a waste of effort and resources (New View, 2000; New View, 2002).

Sexual problems in women are thought to include vaginal dryness and reduced clitoral

sensation due to vascular insufficiency (Park et al, 1997). Although the concept of sildenafil citrate improving sexual function in women with vascular impairment is theoretically sound the New View Campaign explained that female sexual arousal is a complex phenomenon that is dependant on a combination of physiological, psychological and emotional responses (New View, 2002). Although Pfizer abandoned its interest in FSD, sildenafil citrate has been used, off label, by women to improve clitoral tumescence (Murdock, 2000). Irwin Goldstein, an expert in sexual medicine, his associate Jennifer Berman and her sister Laura Berman run a clinic in Los Angeles to treat female sexual problems and promote off label use of pharmacological treatment including Viagra (Berman, Berman and Bumiller, 2001, p 269; O'Connor, 2002).

The pharmaceutical industry has invested heavily in producing drugs to treat female sexual problems and marketing strategies to promote medical therapies for women suggest that FSD is a recognised medical problem (Procter and Gamble, 2004). Testosterone therapy is frequently used in an attempt to improve female sexual desire in women that have been diagnosed with hypoactive sexual desire disorder (DSM-IV, 2000, p 561; Procter and Gamble, 2004; Clayton, 2010). Pfizer recently conducted research into the influence of a selective inhibitor of neural endopeptidase on genital blood flow in women and conclusions from these studies initially suggested that this new compound might restore sexual arousal in women with arousal disorder (Wayman et al, 2010) although updated reports have specified that no further studies are planned due to lack of proven efficacy (Edwards, 2010). It has been suggested that research into the benefits of PDE5 inhibitors in women may have produced unreliable data due to potentially flawed research methodologies therefore further studies on the use of PDE5 inhibitors in women are expected (Rosen, 2010).

We live in an age where human difference is considered to be abnormal and is often identified in diagnostic medical terms (see Meador, 1994 “The Last Well Person”). Medicine continues to pathologise human deviations and promotes the notion that human differences can be “corrected” by the use of drugs or surgical intervention (Moynihan and Henry, 2006). Perceptions of normal sexual function are influenced by personal experience, sexual stories, media articles and carefully constructed advertising campaigns that often depict unrealistic or idealistic images (Brown, Steele and Walsh-Childers, 2002 Rich, 2005; Burgess, Stermer and Burgess, 2007). Investment in advertising by the pharmaceutical industry can be highly lucrative. In 2005 it was reported that for every \$1 expended on marketing drugs such as Viagra \$4.20 was recouped from drug sales (Lenzer, 2005).

Encouraging men to believe that decline in erectile function is “abnormal” regardless of age is likely to increase demand for drugs to treat ED. Media campaigns encourage men to seek help by highlighting that ED might be a sign of serious underlying pathology (Katz and Marshall, 2004; Lexchin, 2006) and provide advice on self-assessment of sexual function and how to identify ED (see <http://www.viagra.com/faqs/faq2.asp>). The prospect of widespread recreational use of medical treatments for ED at the expense of the taxpayer prompted the Department of Health to restrict NHS prescribing of ED treatment (Adam, 1998).

### **Accessing treatment for ED on the NHS**

At the inauguration of the NHS it was suggested that free health care would drain the treasury of all its financial resources (Klein, 2006, p 25 – 41). The introduction of Viagra

influenced political debate on restricting treatment on the NHS and was described as a “test case” for the government in terms of defining policy on health care rationing (Mason and Smith 1994, p 253; Cook and Greenfield, 1998; Chisholm, 1999). Debate on the cost of state funded Viagra overshadowed the potential impact of ED on the lives of men and their partners and disregarded the therapeutic value of ED treatment (Cook and Greenfield, 1998; Baxby, 1999; Beecham, 1999; Dyer, 1999; Smith and Roberts 2000) and the opinions that were expressed by medical professionals during the debate challenged the laws of medical ethics and the professional codes of medical practice (British Medical Association, 1993; Beauchamp and Childress, 1983; Mason and Smith, 1994, p 3-5; Nursing and Midwifery Council, 2008).

The views expressed by GPs, health professionals and health economists on restricting treatment for ED on the NHS were not exclusively influenced by political opinion (Sweeney, 1999; Beecham, 1999; Smith and Roberts, 2000). In a letter to a medical journal a GP suggested that treatment for ED on the NHS amounted to state provision of “sexual activity for a selfish few who refused to pay for their own enjoyment” and suggested that ED was no more stressful than the stress he experienced “when attempting to meet his monthly mortgage repayments” (Sweeney, 1999). It is unlikely that such opinions are inimitable or peerless although it is unfortunate that the GP’s attitude might dictate whether men with ED and their partners obtain adequate assessment and appropriate treatment. The British Medical Association’s handbook of medical ethics (1984) highlights that, “although a doctor may advise on equitable allocation and efficient utilisation of treatment, this duty is subordinate to his professional duty and to the individual who seeks his clinical advice”. Political judgement on managing health care resources does not aspire to Hippocratic ideals and the ethical principles that promote individualised patient care seem to have been abandoned in favour of

utilitarianism.

Sildenafil citrate (Viagra) was launched in the United Kingdom in March 1998 (Adam, 1999a). On the 1st of July 1999 the Department of Health removed all pharmaceutical treatments for ED from NHS prescribing lists and added them to schedule 11 (now schedule 2) of the NHS general medical services legislation (1992). The guidance document specified that NHS prescriptions for ED treatment would only be available in primary care to patients that had been diagnosed with diabetes mellitus, multiple sclerosis, spinal injury, single gene neurological disease, renal failure, prostate cancer, polio, spina-bifida, Parkinson's disease, pelvic injury and prostatectomy (including trans-urethral resection of the prostate) (Adam, 1999b).

The guidance advised that GPs were allowed to prescribe ED treatment on a private prescription for patients that did not suffer from a "listed condition". If ED, in the opinion of the GP, caused the patient severe distress referral to a secondary care specialist centre was advised (Adam, 1999b; Eardley, Sethia and Dean, 1999). Secondary care specialist centres were appointed by the government to assess, treat and maintain treatment for men with ED and "severe distress" although no additional funding was allocated by the government to maintain treatment for this group of patients (Adam, 1999b). According to the Department of Health the guidance on prescribing of ED treatment "set a clear illegibility criteria to ensure avoidance of post-code prescribing" although regional variations in service provision for men with ED was in direct consequence to the government's rationing of ED treatment (Beecham, 1999; Klein and Strum, 2002; Werneke et al, 2005).

Guidance on NHS prescribing of ED treatment failed to meet the requirements of the

European Union Transparency Directive, which states that any exclusion of a drug from a national health system requires a statement of reasons based on objective and verifiable criteria (Council Directive 89/105/EC, 1989). In 1999, Pfizer Ltd used this directive to legally challenge the Department of Health in the English High Court (England and Wales Court of Appeal, *Pfizer versus Secretary of State for Health*, 2002). The court ruled that NHS restrictions on treatment for ED were in breach of European Law (Dyer, 1999). The Health Secretary responded by explaining that the guidance was intended in an advisory capacity and claimed that it was not a legally binding document yet medical treatment for ED has remained on schedule 11 (now schedule 2) of the NHS general medical services legislation (1992) since 1999 (Adam, 1999b; Dyer, 1999).

Prescribing ED treatment on the basis of whether a patient qualifies according to a list of medical conditions distracts attention from the impact of the problem and emphasises that cost restraint is of paramount importance. Assessment and treatment of sexual problems is not included in the Quality and Outcomes Framework (QOF) (Hobbs and Hodgkinson, 2007). Although the Department of Health considers ED treatment to be of low priority in terms of health care provision health deficit associated with ED is difficult to measure. Erectile dysfunction is a non-life threatening disease although it is known to cause marital disharmony and mental illness and has been directly associated with alcohol abuse and suicide (Araujo et al, 2000; Seidman et al, 2001; Bancroft et al, 2003; Ishizu, Ohnaka and Hongkun, 2006). Several studies have identified that ED can cause significant disruption to quality of life (MacDonagh, Porter and Ewings, 2002; MacDonagh et al, 2004; Tomlinson and Wright, 2004).

In addition to the selected list of conditions that disqualifies men with ED from NHS treatment the Department of Health advised that prescribing of ED treatment should be

restricted to one tablet per week (Adam, 1999b). The government's opinion on "normal" frequency of sexual activity was influenced by feedback from a study by Johnson et al (1994, p 137-141) which suggested that in the United Kingdom men and women between the ages of 40 – 70 have sexual activity once per week. These data have been contested yet the government's advice on the frequency of prescribing has remained unchanged (Hurwitz, Cook and Ashcroft, 2003). Contrary to the findings of Johnson et al (1994, p 135 -141) it has been highlighted that frequency of sexual activity is not quantifiable and is thought vary with age (Hurwitz, Cook and Ashcroft, 2003). The World Health Organisation (1986) considers sexual interaction to be integral to an individual's "values, beliefs, attitudes, perceptions and moral codes" and provides no advice on "normal" frequency of sexual activity (WHO, 1986). Encouraging GPs to authorise "normal" frequency of sexual activity disregards human rights (Pfizer versus Secretary of State for Health, 2002) neglects the freedom of sexual expression and disregards the couple's perspective. Almost 70% of men with ED do not have a condition that applies to the selected list (Sairam et al, 2002). Treatment for ED is readily available on the internet and less expensive than the cost of obtaining treatment via a private prescription although there may be associated health risks and despite the pharmaceutical industry having campaigned against the use of counterfeit PDE 5 inhibitors the government guidance does not discourage men from using on-line sources to obtain drugs for ED (Bell, Kravitz and Wilkes, 1999; Fernandez, Green and Newton, 2008; Bate, 2010).

Political guidance on prescribing of ED treatment contradicts the government's pledge to negotiate inequality in health care provision (Yamey, 1999; Davey-Smith, 2000; Moscrop, 2009). The NHS survives by utilitarian ethics and by prioritising finances in terms of meeting "important" health care objectives (Mill, 1951). It has been highlighted that physicians should show allegiance to their patients in favour of budgetary concerns when

prescribing treatment of proven safety and efficacy (McKneally et al 1997). This opinion is consistent with Kant's (1972, p 63-65) theory of rights in determining moral worth and emphasises the patient's right to access treatment on the basis of clinical need, which is an integral aspect of deontological theory and is relevant to the doctor's code of clinical practice. Dr. Ian Bogle, chairman of the British Medical Association, in response to the government's suggestion that ED did not cause pain or threaten life stated "if those were the criteria for providing patients with appropriate treatment, it would exclude most of my life's work" (Beecham, 1999).

Opposing political parties may appear to support different policies on health care provision although both Labour and Conservative governments have historically endorsed utilitarian ethical principles. In 1994, Robin Cook, (the Labour Party health spokesman), stated that, "the NHS represented a brave assertion of the equal value of human life by ensuring that patients got the treatment they needed rather than the treatment they could afford." He emphasised that "Conservative reforms were dehumanising and contemptuous for any concept of professional ethics" and accused the Thatcher government of "rule utilitarianism", which in this context challenged the ethics of a two tier health service or privatisation of the NHS (Mill, 1951). The Labour party however introduced the restrictions on prescribing of ED treatment (Adam, 1999b). In the guidance document the Department of Health stated that "the move to restrict the treatment of ED was not rationing but the controls would ensure that expenditure on treatment for ED was limited to reflect its priority" (Spalding and Watson, 1999). Rehabilitation of patients with mental illness and associated social phobia, in recent years, has been prioritised in terms of NHS funding and although ED is common in men with mental health problems, mental illness is not included on the selected list (Ponniiah and Hollon, 2008). Treatment for ED in patients with social phobia is available only on

private prescriptions or via a hospital clinic and a lengthy waiting list.

Evidence from the debate on rationing of ED treatment suggests that the GP's opinion may influence access to treatment in primary care (Sweeney, 1999). The government guidance on medical treatment for ED does not include information on the potential consequences of ED and does encourage GPs to consider the patient's predicament (Adam, 1999b). The guidance document focuses entirely on the issue of prescribing, which influences opinion that ED is a male medical problem. Criteria that define severe distress are ambiguous statements that are open to interpretation which encourages disagreement and debate on whether the patient qualifies for treatment (Adam, 1999b). Apart from providing instructions on frequency of sexual activity for couples the guidance document does not consider partners of men with ED. Neglecting to mention partners encourages the notion that ED is a male medical problem. Feedback from the literature on the medicalisation of human sexual function highlighted that women challenged medical definitions of female sexual problems (Tiefer, 1996; Tiefer, 2002). Evidence that medicalisation of male sexual function is accepted by men is reflected in the commercial success of erectogenic treatment (Hatzichristou et al, 2000; Brock et al, 2007; Chevret-Measson, 2004; Lexchin, 2006).

The selected list includes chronic disease states such a Parkinson's disease, prostate cancer and diabetes although vascular disease was excluded (Adam, 1999b). The government have never explained their logic in identifying the conditions that qualified men with ED for NHS treatment.

### **The effects of chronic disease states on sexuality and relationships**

It is reasonable to suggest that there may be similarities between the impact of ED on a couple's relationship and the impact of chronic disease on the lives of women and their partners. Erectile dysfunction is often described as a chronic disease and chronic illness is known to influence sexual and relationship problems (Samelson and Hannon, 1999; Latini et al, 2003). Chronic disease such as atherosclerosis, diabetes mellitus, Parkinson's disease and multiple sclerosis is known to cause ED and other sexual problems and ED is known to be a precursor to chronic illness including ischemic heart disease (Bancroft, 1989, p 376-380; Porst, 1996; Eardley and Sethia, 2003, p 2-4; Solomon, DeBusk and Jackson, 2005).

It has been reported that healthy individuals avoid romantic encounters with people that they know to have a chronic illness therefore patients with chronic disease may find it difficult to establish relationships (Joachim and Acorn, 2000). The impact of chronic disease on couples is known to be associated with deterioration of the patient's health and the amount of help that the patient requires with activities of daily living (Newsom and Schulz, 1998). These factors are thought to be significant in terms of influencing marital conflict, self-esteem, distress and fatalistic beliefs (Folkman and Moskowitz, 2004). The partners role often changes to that of a carer and adjusting to role change may be difficult for both partners and may affect sexual relations (Cliff and MacDonagh, 2000; Helder et al, 2002). Loss of sexual desire may manifest in both partners when couples attempt to adjust to the impact of chronic disease (Samelson and Hannon, 1999). Lower care giving burden is associated with reciprocity of support among care-giving wives and higher levels of marital satisfaction, which reflects opinion that severity of disease in terms of its impact on the patient's health is likely to determine the level of adjustments couples make to their lives when coping with chronic illness (Wright and Aquilino, 1998).

Samelson and Hannon (1999) suggested that loss of sexual desire in patients with Parkinson's disease, lupus, multiple sclerosis, erythematosus and diabetes mellitus" is associated with "fatigue, disease severity, medical treatment and fear". It was recommended by Samelson and Hannon (1999) that "counsellors" should address the underlying cause of sexual problems in patients with chronic disease in order to improve sexual function however fatigue is unlikely to be resolved by counselling. Erectile dysfunction is common in men with chronic disease although if ED is influenced by fatigue or loss of sexual desire erectogenic treatment may be of little benefit (Eardley and Sethia, 2003, p 2-4; Fowler et al, 2005).

Anderson and Wolf (1986) highlighted that sexual problems resulting from chronic illness are often overlooked by health professionals. This article suggested that psychological "interventions" are required to "meet the sexual needs" of couples that experience sexual problems when coping with chronic illness although it is highlighted that sexual problems in patients with chronic disease are often influenced by organic aetiology. Anderson and Wolf (1986) highlighted that "psychological processes of cognitive appraisal, emotional expression and coping strategies that are triggered by chronic disease play a vital role in sexual adaptations". However adaptation to change in body image is not inevitable. Resolution of sexual problems associated with chronic disease may not be achieved however facilitation of communication between partners and couple counselling may help couples deal with and accept sexual problems (Aubin and Heiman, 2004; Perelman, 2005).

Studies on the impact of chronic disease on couples frequently refer to dyadic evaluation of chronic illness often when feedback has been obtained from only one partner (Berg and Upchurch, 2007). Similar bias exists in studies that reported on ED and its treatment

from a couple's perspective but obtained opinion on partner issues from men (King et al, 2007; Farca et al 2008; Cappelleri et al, 2008). Masters and Johnson (1970, p 2) suggested that assessment of sexual problems is likely to be incomplete if both partners are not considered and in a study on the impact of chronic disease Bodenmann (2005) advised that in order for feedback to be accurate marital relationship appraisal must consider the experiences of both partners. Emotional disclosure between patients with chronic disease and their partners is thought to help couples avoid frustration, isolation, distress and depression (Manne et al, 2004; Manne et al, 2006). Poor communication has been associated with conflict, poor adjustment to living with chronic illness and negative behaviour, particularly among female partners (Manne et al, 2005). Spousal support has a positive effect on the mood of both partners when coping with chronic disease (Manne et al, 2005). Marriage is thought to enhance physical and mental health although disruption to the marital relationship has been reported to cause distress and significant health deficit (Kiecolt-Glaser and Newton, 2001). Relationship stability has been found to be an important marker in predicting the future health status of both men and women (Kiecolt-Glaser and Newton, 2001).

A study conducted in the Netherlands by Baanders and Heijmans (2007) looked at the impact of chronic disease on the lives of 1,093 healthy partners. Partners of patients with chronic disease were recruited from 51 general practices. Data was collected by postal questionnaire. Questionnaires were completed by participants at 6 month intervals from 2001-2003 and focussed on 4 specific impact factors including personal life strain, social relations, financial burden and intrinsic rewards. Sixty percent of participants assumed the role of caregivers although only 4% became involved in their partner's personal care. Two-thirds of partners reported intrinsically rewarding aspects of living with a chronically ill person. Intrinsic rewards were more evident in partners of patients that

experienced minor disruption to their activities of daily living. More than 40% of partners stated that they experienced significant strain on their personal life and approximately 20% reported that coping with their partner's chronic illness upset their social life. Female partners reported a higher burden in all 4 impact factors therefore according to this study women were more disturbed than men when coping with their partner's chronic disease. These findings are supported in other studies (Lutzky and Knight, 1994; Lyons et al, 2002; Hagedoorn et al, 2000). Baanders and Heijmans (2007) concluded that female partners experienced a higher level of burden due to women being inherently more sensitive (than men) to the well- being of others.

It has been suggested that women are likely to be more satisfied with their lives if they express emotion when coping with chronic disease (Folkman and Lazarus, 1980; Stanton et al, 1994). These findings, however, have only been evident in short term studies (< 3 months) (Stanton et al, 2000). Women often assume a nurturing role when their partner has been diagnosed with chronic illness (Maccoby, 2002) although historical changes in the societal status of women may have influenced younger cohorts of women to be less nurturant (Twenge, 2001). Couples that negotiate chronic illness together fare better in terms of dealing with the consequences of chronic disease (Cutrona, 1996). Positive validation, warmth and love create a positive environment whereas negative opinion is associated with poorer coping responses (Mann et al, 1999).

Collaborative problem solving among couples that are faced with adjusting to the impact of chronic disease is enhanced by egalitarian interactions (Berg et al, 2003) and less evident in couples that include a dominant and controlling partner (Miller and Bradbury, 1995). A couple's approach to coping with chronic disease is thought to be influenced by the nature of the illness, the age of the couple and the onset of the illness. For example

coping with the consequences of myocardial infarction due to its sudden impact may be more difficult than coping with the consequences of slow-onset disease.

Chronic disease may disrupt core aspects of a couple's relationship. Joint participation in social activities may be impossible due to physical disability and cognitive impairment may adversely affect a patient's ability to communicate (Berg and Upchurch, 2007). The impact of chronic disease on sexuality and sexual function is often considered in studies that are specific to conditions that affect sexual organs such as prostate disease and breast cancer (Hannah et al, 1992; Andersen and Lamb, 1995). Treatment decisions are often shared by patients with chronic disease and their partners (Baider and De-Nour, 1999) although reluctance among men with prostate cancer to be involved in treatment decisions has been reported to negatively affect their partner's ability to cope with the disease (Manne et al, 1999). These studies highlighted that communication between women and their partners is an important aspect of how couples cope with chronic disease. Relationship dynamics have been reported to influence psychological adjustment to the impact of chronic illness (Manne et al, 1999; Berg and Upchurch, 2007). "The interdependence of couples affects appraisal of illness, shared appraisals of specific stressors, and the ways couples cope dyadically" (Berg and Upchurch, 2007). Lack of information on the impact of ED from a couple's perspective influences uncertainty in terms of whether this statement applies to how couples cope with ED. Erectile dysfunction is a chronic disease that impacts on masculinity and alters perception of body image (Witt, 2004; Mahowald, 2009) therefore it is reasonable to suggest that there may be similarities in the way couples cope dyadically with chronic illness and ED although there are no studies that have considered the impact of ED on couples in this context.

Quantitative research has produced limited information on the impact of ED on women

and there are no studies that have looked at how women and their partners cope with ED prior to treatment being considered. Individual opinions of women and their partners on the impact of ED and its treatment may be irrelevant when the problem is looked at from a couple's perspective (Nelson, 2006; Wylie and Machin, 2007; Riley 2008).

### **Gaps in the knowledge of how ED affects women and their partners**

Although couple samples have been included in quantitative studies of ED and its treatment these studies provided limited insight into the impact of ED on the lives of women and their partners (Paige et al, 2001; Fergus, Gray and Fitch, 2002; Latini et al, 2002; Latini et al, 2003; Tomlinson and Wright, 2004; Fisher et al, 2005b; Goldstein et al, 2005). Psychometric assessment and surveys have identified conflicting opinions among women and their partners on the impact of ED and its affect on sexual activity although these studies did not provide information on how conflict between partners affected the lives of couples or its influence on treatment decisions (Cameron and Tomlin, 2007; McCabe and Matic, 2008; Chevret-Measson, 2004; Rosen et al, 2006). Feedback from psychometric assessment in these studies was limited in terms of explaining the significance of these data and neglected enquiry into the realities that contributed to the opinions of women and men. Women denied sexual problems despite acknowledging sexual pain and despite their partners reporting that they experienced ED (Chevret-Measson, 2004; Rosen et al, 2006). Men with ED in these studies considered treatment when their partners were not convinced that treatment was required (Rosen et al, 2006; Brock et al, 2007). If couples had been interviewed and encouraged to discuss the opinions they expressed in feedback from questionnaires perhaps treatment for ED would have been reconsidered.

Constructing reality from personal beliefs and assumptions about sexual interaction and

sexual performance may be influenced by lack of communication about sex and mass exposure to unrealistic media representations of sexual norms (Lexchin, 2006). It is important to note that researchers and journalists also construct reality from personal beliefs and assumptions that have been formed from being exposed to similar social stimuli (Lythcott and Duschi, 1990). It is reasonable to suggest that although research into the impact of ED on men has been extensive (Porst 1997b, Seidman et al, 2001, MacDonagh, Porter and Ewings, 2002; Meyer et al 2003; MacDonagh et al 2004; Sand et al, 2008) knowledge that has been gained from these studies may be limited by neglecting the couple's perspective on the problem and how to deal with it. Feedback from these studies on the realities men face when they experience ED may be inaccurate if men that participated in these studies provided information on the impact of ED with little or no knowledge of how ED affected their partners.

Research into ED has been largely influenced by medical treatment. The literature review revealed no studies that obtained subjective accounts from women and their partners on the impact of ED. There were no qualitative studies that obtained opinions on ED and its treatment from heterosexual couples and there were no studies that looked at the impact of ED on couples and obtained subjective opinions on the problem from both partners without focussing on the prospect of treatment.

### **Chapter 3**

## **Study Design and Methodology**

### **Choosing a qualitative study design**

I chose a qualitative study design in order to gain insight into how ED affects the lives of women and their partners. The literature review revealed no qualitative studies on the impact of ED that included obtaining opinions on the consequences of ED from couple samples. The literature review revealed gaps in knowledge on the impact of ED on women. Whilst qualitative research has been criticised due to the prospect of the researcher becoming personally involved in the research enquiry (Denzin and Lincoln, 2005, p 21) it has been suggested that in qualitative research the researcher is inevitably involved in the research and affects the research outcomes (Stanley and Wise, 1993, p 115; Mauthner and Doucet, 1998: p 127; Carolan, 2003).

Quantitative research provides valuable objective information on ED and its consequences but is less sensitive to providing subjective feedback on how ED affects the lives of women and their partners. This opinion is supported in studies where questionnaires identified that men experienced ED and their partners denied sexual problems despite couples being recruited to provide information on the impact of ED and men with ED seeking erectogenic treatment (Rosen et al, 2006; Chevret-Measson et al, 2006). These studies did not provide information on why women and their partners provided conflicting information about their sexual function.

### **Identifying a method of data collection**

When conducting qualitative research, flexibility in study design is recommended in order to create an environment that is likely to be conducive in terms of obtaining quality

feedback from the study participants (Sidani and Sechrest, 1996). The sexual nature of my research enquiry restricted my options when identifying a method of data collection. I chose to interview women on a one to one basis and I was able to conduct interviews in a private environment which maintained confidentiality. Other methods of data collection may have been considered inappropriate by women or may have influenced reluctance among women to disclose information about their predicament. I explain in more detail why I rejected other methods of data collection later in this chapter.

My research enquiry was influenced by lack of knowledge of how ED affected women. I considered the possibility that the impact of ED on women was likely to affect how men adjusted to living with ED although there was no evidence to support this opinion in the literature review. I came to the research with a loose collection of assumptions about the impact of ED on women and decided on a method of data collection that provided an opportunity for women to provide accounts of the impact of ED on their lives. One to one semi-structured interviews in a private and confidential environment has been identified as an appropriate method of data collection in terms of encouraging research participants to express their views (Weber, 1949; Becker, 1996).

I decided against focus groups as women may have been reluctant to participate in an open forum discussion about sexual issues. The literature review revealed mixed opinion on the principles of phenomenology and information on phenomenological study design was confusing (Koivisto, Janhonen and Vaisanen, 2002; Finlay, 2009; Norlyk and Harder, 2010). It has been reported that research methods in phenomenological studies often fail to represent the true principles of phenomenology (Koivisto, Janhonen and Vaisanen, 2002; Wertz, 2005). Phenomenological research is thought to be phenomenological when it involves “rich description of the life-world or lived experiences and where the

researcher has adopted a special, open phenomenological attitude” (Findlay, 2009).

Giorgi (2008) suggested that phenomenological observation required the inclusion of at least three participants. I rejected the concept of phenomenology as conflicting opinion on its principles made it difficult to understand and I was not convinced that I would have achieved my research objectives by obtaining information on the impact of ED from such a small sample size due to the prospect of women being reluctant to disclose information about sexual issues. Studying consciousness as experienced by the participant was less appealing to me than grounded theory and a structured method of analysing feedback from interviews (Strauss and Corbin, 1990; Creswell, 1998). My research objective was to gain insight into the impact of ED on women and their partners. Case studies may have produced feedback consistent with Plummer’s (1995) opinion on sexual stories and may be an appropriate method of data collection for future studies.

I chose to tape-record interviews with women and document feedback from interviews with men by taking notes. Following my decision to tape-record interviews with women and transcribe recordings, the issue of researcher bias was discussed with personnel from NHS Ayrshire and Arran research and development department and my supervisors from the University of Central Lancashire. To negotiate the issue of researcher bias it was suggested that I recruit an external researcher to conduct interviews and transcribe the data. I declined this suggestion as it would have been extremely difficult to locate someone that possessed adequate knowledge of the issues relating to ED that women were likely to ask about.

### **Symbolic interaction and sexual relations**

My thesis was underpinned by symbolic interaction theory, which provided a theoretical

framework that was relevant to my research. The symbolic interaction perspective refers to how humans allocate meaning to the world and its contents by processing and developing a complex set of symbols that evolve from interactions with people, society and the self (LaRossa and Reitzes, 1993). Opinion on “normal” sexual behaviour has been influenced by religious, medical and legal authority (Peiss, 1986, p 244; D'Emilio and Freedman, 1988, p 428). Our reluctance to communicate about sex and sexuality is influenced by lack of knowledge on “acceptable” sexual behaviour and the stigma that is associated with being sexually deviant therefore disclosure about issues that relate to sexuality and sexual preference is often avoided (Stone and Levine, 1950; Peiss, 1986, p 244; D'Emilio and Freedman, 1988, p 428). We wear masks to influence the perception of others and we conform to the laws of society by displaying behaviour that we consider to be socially acceptable (Blumer, 1969).

Kinsey (1947) highlighted that sexual interaction was symbolic and influenced development of sexual meaning and his research into human sexuality in the 1940s provided perspective on “normal” sexual behaviour. Masters and Johnson (1970) provided information on human sexual relations and in the 1970s. “Human Sexual Inadequacy” became a best seller and opinion on “normal” sex continues to be influenced by media sources (Atwater, 1987). Establishing meaning by identifying symbols during interaction influences our development and understanding of our role in society (Blumer, 1969; LaRossa and Reitzes, 1993). “The symbolic meanings associated with sexuality affects how we think about ourselves, relate to others and how others think and relate to us” (Longmore, 1998). An erect penis symbolises manhood therefore men with ED lose perspective of their role in society due to suppression of their sexual identify (Colson, 2005; Fisher et al, 2005b).

Roles within a relationship or marriage are symbolic in terms of communication and represent “collections of expectations that define regularised patterns of behaviour” (Peterson, 1987). Within a marriage there is almost always a “nurturer, a socialiser, a provider and a decision maker” (Peterson, 1987). Women are more likely to assume the role of “nurturer” and men are likely to be “providers” (Maccoby, 2002; Witt, 2004). These roles or symbols reflect opinion on the constructs of masculinity and femininity and identify with the development of self-concept (Witt, 2004; Mahowald, 2009). Self-concept is developed “by our interactions with others, our observations and interpretations of how significant others react and by our perceptions of their reactions” and is an important aspect of motivating human behaviour (LaRossa and Reitzes, 1993). George Herbert Mead suggested that human beings enhance their development by talking about their inner experiences such as thoughts and desires and interpret symbols with common meaning when analysing feedback from discussions (Morris, 1967, p 133). Human beings, however, find it difficult to talk about sex and during social interaction, rarely disclose details about their sexual desires and sexual activities (Atwater, 1987). Symbols with common meaning, according to Mead shape the self by reinforcing our beliefs and opinions and aggregations of our social interactions shape society by influencing social organisation and social behaviour (Morris, 1967, p 135-143).

Interaction constantly changes social organisation, as symbols with common meaning are reviewed, discarded and replaced, influencing change in opinions, attitudes and behaviours (Longmore, 1998). In the United Kingdom masturbation is no longer considered to be a sexual problem although subjective opinion on whether it is “acceptable” or “normal” varies (English, 1957; Conrad and Leiter, 2004). The pharmaceutical industry attempted to influence perception of “normal” sexual function by focussing on the physiological aspects of the male sexual response and promoted ED treatment by highlighting that better erections inevitably produced “better sex” (Lexchin,

2006; Mulhall et al, 2008). It is reasonable to suggest that such opinions are rarely contested due to people's reluctance to express opinions about sexual interactions and sexual relationships.

It has been suggested that men consider erectile function to be symbolic in terms of developing or maintaining self-concept and communicating with others (Tomlinson and Wright, 2004; Fisher et al, 2005b; Rosen et al, 2006; Laumann et al, 2007; Sand et al, 2008). Feedback from these studies highlighted that men considered treatment for ED to be integral in terms of "solving the problem". There are no studies that have looked at symbolic meaning associated with ED from a woman's perspective. Men are often reluctant to discuss their views on the impact of ED with their partners (Colson, 2005; Fisher et al, 2005b) therefore women may have few sources of information on which to rely upon when attempting to allocate meaning to their predicament when dealing with the consequences of ED.

### **Choosing grounded theory**

Grounded theory was developed in the 1960s by Barney Glaser and Anselm Strauss (1967). Glaser and Strauss (1967) developed a constant comparative method of collecting, analysing and reporting data and considered that the researcher's opinions attitudes and beliefs influenced the research outcomes and conclusions. When qualitative research became popular grounded theory was criticised as being an ill-defined, non-scientific research methodology and was deemed inadequate in terms of its application to qualitative study design (Haig, 1995; Miller and Fredericks, 1999; Rennie, 2000; Urquhart, 2001; Charmez, 2003). In order to conform with the principles of qualitative research, Strauss (1987) (and Strauss and Corbin, 1990) redefined grounded theory as a systematic method of data collection and data analysis and introduced a framework to

constantly compare concepts in the data in order to establish connections between categories of concepts and the phenomenon of interest. Glaser (1992) argued that Strauss (1987) had oversimplified grounded theory and neglected its versatility by identifying it as a qualitative research method. Glaser (1992) believed that grounded theory was flexible and applicable to various research methodologies.

The objective of my research was to gain insight into the impact of ED on women and their partners. I had formed opinions on how ED affected women by relying on clinical experience although my clinical experience provided limited information. When interviewing couples women were always in the presence of their partners and when referring patients with ED to my clinic GPs rarely considered the impact of ED from a couple's perspective. I had not previously interviewed women on a one to one basis and data from the literature review did not provide information on ED from a couple's perspective. Strauss and Corbin (1990) provided a framework that in theory was capable of producing information on the impact of ED on women and identifying causative factors in relation to the problems women experienced. Furthermore grounded theory applied to my qualitative study design and provided a structured method of analysing feedback from transcriptions of interviews with women (Giorgi, 1994; van Manen, p 77-110, 1990).

### **Obtaining ethics approval**

Ethics approval was obtained from the University of Central Lancashire (Faculty of Health Ethics Committee) and NHS Ayrshire and Arran Local Research and Ethics Committee (LREC). LREC approval was obtained in conjunction with approval from the West of Scotland Central Office for Research and Ethics. Members of LREC expressed concern in relation to whether I would be able to recruit an adequate population sample

of women due to the sexual nature of my research enquiry. I did not encounter difficulties recruiting women for research interviews. Only minor changes to the study protocol were requested by the University of Central Lancashire and by NHS Ayrshire and Arran Local Research and Ethics Committee.

### **Exclusion criteria**

I excluded men and women under 18 years of age. Although my intention was to recruit couples that were cohabiting and in a long term, stable relationship, measuring relationship stability presents with obvious difficulties (Goodman and Greaves 2010). It has been reported that married couples are more likely to be in a stable relationship than couples that are cohabiting (Benson, 2009; Goodman and Greaves, 2010) although I did not exclude couples that were cohabiting on the basis of these findings. (All of the couples that participated in the study were married and had lived together as married couples for more than 5 years). I excluded men that presented with ED secondary to another sexual problem as it was appropriate to address the other problem. Although these men had been referred with ED improvement in erectile function often occurs in conjunction with resolution of other sexual problems. Also excluded were men that experienced ED for less than 6 months duration, men with signs and symptoms of underlying pathology and women with acute physical or psychological problems. Patients with underlying disease required further assessment and treatment of underlying conditions or were referred for specialist assessment of the problem. I excluded women with sexual problem (and sexual pain) as sexual problems in women might cause their partners to experience ED (Rosen et al, 2006).

### **Inclusion criteria**

I recruited men with IIEF, EF domain scores of less than 11 which identified severe ED

(Rosen et al, 1997). Information on severity of ED was obtained from interviews with men prior to inviting their partners to participate in the study. My research objective was to gain insight into the impact of ED on women therefore my intention was to recruit men that had identified significant deterioration in their erectile function. IIEF scores of more than 11 indicate mild/moderate ED (Rosen et al, 1997). Partners of men with mild/moderate may deny sexual problems (Rosen et al, 2006). All of the men I recruited provided information that identified severe, organic ED.

I focussed my research on heterosexual couples. The literature review provided limited information feedback on the impact of ED on heterosexual couples. Recruitment of an adequate population sample of homosexual couples would have been difficult due to the small numbers of homosexual couples that attend my clinic for routine clinical interviews. I highlighted in chapter 2 that research has looked at the impact of ED on men although there is lack of knowledge and understanding of how ED affects women, which affects understanding of the impact of ED on couples.

### **Recruitment of women and their partners**

I interviewed men with ED that were referred by their GP to my clinic for assessment and treatment. If men with ED met the inclusion/exclusion criteria I invited them to participate in the study and I explained that my research project included conducting interviews with their partners. Men read information about the study including details about the interviews I planned to conduct with their partners and those that agreed to participate were given written detailed information about the study to take home for their partners to read. Information for women included details about the study including the research methodology and their participation in one to one interviews (Appendix 1). Men were given my contact number prior to leaving the hospital and if their partners agreed to

be interviewed an appointment was arranged by telephone. Women were encouraged to use my telephone contact number if they required information about the study. Consent forms were signed by women and their partners prior to women participating in interviews. Women were given the opportunity to decline participation in interviews when they attended their appointments and were advised that when they signed their consent form their participation in interviews was at their discretion and women were advised that they could stop the interview at any time.

### **Informed consent**

Detailed written information about the study was issued to all participants and consent forms were signed by both partners and witnessed by the Chief Investigator prior to women being interviewed (Appendix 2). Information included details on maintenance of confidentiality. Participant information and consent forms were approved by the Local Research and Ethics Committee (LREC) and NHS Ayrshire and Arran Research and Development department.

### **Analysis (Using grounded theory)**

#### **Open Coding**

Data were coded manually from transcriptions and included notes and memos that identified non-verbal communication and context and meaning of rhetoric. Colours, symbols, letters, abbreviations and headings were used to identify concepts. Concepts overlapped, disconnected, re-connected and merged into other groups of data and as data collection progressed new groups of concepts emerged. Categories of concepts were split into several relevant parts. Data from transcriptions were also cut and pasted into similar groups using Microsoft word and manual comparisons using labels, codes and line diagrams. Constant comparison of concepts opened new avenues of enquiry. I used

headings to label categories of concepts and line diagrams to identify connections between categories. Over 50 sub-categories and categories emerged from the groups of concepts prior to refining the data in terms of its theoretical relevance to the phenomenon. Relationships in the data were the foundations of the key categories or categories with significant theoretical properties in relation to the phenomenon of interest (see appendix 5).

### Axial Coding

Theoretical properties of the categories were analysed and causal conditions/active variables and background variables were identified. Relationships between the categories of concepts, causal conditions and the phenomenon of interest were established. I used a basic framework that included the headings, “phenomenon”, “causal conditions” and “context” to sort the data and this allowed visual interpretation of the connections between concepts (Appendix 5). Categories with the strongest theoretical connections to the phenomenon of interest emerged to form the key categories. Six key categories were identified.

### Selective Coding

Explicit relationships and connections between the key categories were established by comparing theoretical concepts in the data. The category that made the most explicit connection in terms of its theoretical relevance to all of the other key categories and the phenomenon of interest emerged as the core category. Analysis of the data began with pages of words with hidden concepts. I compared the experience to looking at a blurred landscape through a camera lens and adjusting the focus until the distorted image became clear, sharp and defined. The core category was dominant and flexible and had distinct connections with the phenomenon.

### Theoretical Sampling

The core category and its relationship with the phenomenon of interest was tested by theoretical sampling. The categories of concepts were dismantled and the data was analysed in order to establish new connection between concepts. Theoretical sampling confirmed the key categories and established the core category's dominance in terms of its relationship with the other categories and the phenomenon of interest.

## **Results**

### **Introduction**

In this chapter I explain how I calculated the size of the population sample and I present demographic data and other results relating to the population sample. I then present the results from the interviews I conducted with men. I did not tape interviews with men and although I identified themes from written notes that I took during interviews I do not use direct quotes when presenting these results. The next section in this chapter includes the results of my interviews with women. I use the headings or themes from the key categories of concepts that developed from coding data using grounded theory to present the results of my interviews with women. I support the key categories or themes I identified in chapter 3 with quotes from transcriptions. I then compare feedback on the impact of ED from women and their partners.

### **Research participants**

The sample size was dictated by the theoretical relevance of the data from transcriptions of taped interviews with women. New avenues of enquiry became redundant after analysing transcriptions from 14 interviews. I interviewed 15 women. Coding of feedback from the 15<sup>th</sup> transcription confirmed that data saturation had occurred and no further interviews were required.

I interviewed 27 men that met the inclusion criteria. Six men declined to participate in the study. These men stated that their partners would decline invitations to participate in interviews. Two men explained that their partners would not have time due to work commitments. Three men said their partners would be embarrassed and 1 man was told by his partner that it was his problem and he should “fix” it. Twenty-one men agreed to participate in the study and their partners were invited to participate in one to one

interviews. Fifteen of these 21 women participated in one to one interviews. Only 2 women refused to be interviewed. Four women agreed to participate in the study and arranged appointments to be interviewed but failed to attend. Two women withdrew their agreement to be interviewed by telephone and 2 women rearranged interviews but failed to attend. Of the 27 men with ED that were interviewed and met the inclusion criteria only 3 of these men were accompanied at interviews by their partners. All of these women agreed to participate in the study and participated in one to one interviews at a later date.

The study adhered to projected time scales, research protocols and the conditions that were stipulated by LREC and the West of Scotland Central Ethics Office and research documents were audited by NHS Ayrshire and Arran Research and Development Department.

### **Demographics**

The age range of men was 47-86 years (mean age = 59 years). The youngest woman was 31 years and the oldest was 70 years (mean age = 55 years). All of the couples that participated in the study were married and had been married for more than 5 years. Duration of ED among men varied between 1 and 10 years (mean duration = 3.4 years). All of the men that participated in the study had severe ED according to the IIEF although 1 man described severe ED but was not allocate an IIEF score. The notes I made when interviewing this man suggested that his IIEF score was omitted due to human error. Eight of the women I interviewed were post-menopausal, 4 were peri-menopausal and 3 women were pre-menopausal. All participants were white British citizens from villages within the counties of Ayrshire.

### **Interviews and transcriptions**

I ensured that the environment was private and quiet and I avoided face to face discussion during interviews. I reinforced to the participants that confidentiality was of paramount importance and explained that withdrawal from the study was at their discretion. Interviews with women varied between 30 minutes and 90 minutes. I arranged interviews with women when routine clinics were not in progress in order to maintain privacy and confidentiality.

I was concerned that taping of interviews might have influenced reluctance among women to participate in discussion and although initially women seemed conscious of the tape recorder they appeared to disregard its presence as interviews progressed. Data was lost during one interview when the tape recorder stopped and during another interview the tape completed its cycle before the interview ended. One of the tapes split when transcribing data although the transcription was almost complete.

Transcribing data from tape recorded interviews with women was an important but arduous task and a time consuming part of my research. Transcription is often referred to as “a chore” (Agar, 1996) although it has also been described as “a pivotal aspect of qualitative enquiry” (Oliver, Serovich and Mason, 2005). Transcription practice is thought to consist of two dominant modes that are part of a continuum. Naturalism refers to transcribing of every detailed utterance that occurred during the research interaction (including silences) and denaturalism, which describes the removal from transcriptions of all idiosyncrasies (Oliver, Serovich and Mason, 2005). The naturalised approach is thought to be representative of real world phenomenon due to its verbatim depiction of speech (Schegloff, 1997). Denaturalised transcription suggests that within speech there are meanings and perceptions that construct our reality (Cameron, 2001). I chose a naturalistic approach to transcribing of the data and I recorded non-verbal feedback,

silences and body language that contradicted rhetoric. My interpretation of feedback from women was influenced by gender, the environment and the symbols I identified with when forming opinions on my interaction with women during interviews. I discuss the relevance of my influence on the data from research interviews in chapter 5 of this thesis.

All of the women that participated in the study were allocated numbers that related to transcriptions and the numbers were matched with the notes obtained from interviews with their partners. The numbers were allocated to participants by the Chief Investigator and had no relevance in terms of linking women and their partners to the study. Audio-tapes are locked in a secure location to which only I have access and will be stored in the future under the terms and conditions of data storage according to the West of Scotland Central Ethics Office and NHS Ayrshire and Arran research and Development Department. The first and second tape recordings of interviews with women including transcriptions were critically reviewed by my Director of Studies (Professor Alan Riley) at the University of Central Lancashire. The tapes were hand delivered and returned to me at a scheduled meeting with my supervisors. No significant change to the format or structure of interviews was recommended following review of the tape recordings and transcriptions.

### **Results of interviews with men**

Feedback from interviews with men was documented in their hospital notes. Interviews with men lasted between 30 and 50 minutes. Interviews were semi-structured and included questions that I routinely ask during clinical assessment. I asked men about the impact of ED on their lives and specifically asked about the affect of ED on their partners. I also asked men about their motivation to seek treatment and whether seeking treatment

involved their partners. I identified 7 common themes relating to ED and its consequences from the information I obtained from interviews with men.

### Themes from interviews with men

**1. *Identifying and solving the problem:*** Men identified “the problem” almost exclusively in terms of physiological deficit and their perception of solving “the problem” focussed on restoration of their erectile function. Although men presented with other problems associated with ED resolution of these problems was thought to hinge on restoring their erectile function. Men were aware that “hormones” influenced sexual function and considered “Viagra” to be an appropriate treatment option. Men assumed responsibility for “solving the problem” despite their reluctance to communicate with their partners and they “blamed” themselves for situation. Embarrassment and perception that their sexual function might improve spontaneously prevented men from seeking help.

**2. *The impact of ED on masculinity:*** Men expressed that they has lost their “manhood, confidence and self-esteem” and use terms such as “useless” and “humiliated” to describe their feelings. Men said they felt hurt and embarrassed when they failed to obtain an erection. Men informed me that they avoided intimacy with their partners as intimacy was part of sexual activity and complained that penile shrinkage affected their confidence and influenced feelings of inadequacy. Failure to “perform” caused men significant upset.

**3. *Perception of the impact of ED on partners:*** Men declared that their partners no longer offered them respect because of their inability to function as a man. It was suggested by men that their partners were aware of their intentions to commence on treatment for ED. Most of the men I interviewed stated that they had discussed treatment

with their partners. Men acknowledged deficit in communication with their partners but highlighted that their partners “missed” having sex. Most of the men I interviewed believed that their partners were upset due abstinence from sexual activity causing sexual “frustration”.

**4. *Expectation of ED treatment:*** Men expected to be prescribed Viagra and expected Viagra to “cure” them. Men expected Viagra to restore their erectile function and did not contemplate the possibility of failure. It was expected that restoration of erectile function would improve the relationship with their partners and solve the problems associated with ED.

**5. *The impact of failure:*** Statements such as “I am a burden to my wife” were used by men to describe their predicament. Men worried about the impact of failure on their relationship and stated that ED affected every aspect of their lives. Although their partners made comments that were intended to make them feel better attempts by women to console men caused more upset for men.

**6. *Aetiology of ED:*** Men with ED generally disregarded the possibility of underlying pathology as a potential cause of ED. The effect of smoking on erectile function was poorly understood. Medication was blamed by men for causing ED but they struggled to accept that ED might be influenced by the ageing process. Men often stated that ED was “psychological” and that they needed a “kick start” although all of the men I interviewed experienced organic ED. Men were convinced that their erectile function would return to “normal” prior to deciding to seek help and were unaware of the incidence of ED in men of similar age.

**7. Age and sexual function:** Reluctance to seek help was influenced by age. Men assumed that they would be judged by their GP in terms of their age and told they were too old to be prescribed ED treatment. Although men acknowledged that other physical capabilities were affected by age most of the men I interviewed did not associate deterioration in sexual function with the ageing process. Age was deemed to be a barrier to seeking help for ED.

### **Results of interviews with women**

Nineteen months elapsed from the 1<sup>st</sup> to the 15<sup>th</sup> interview with women. All of the women I interviewed became very emotional when talking about the impact of ED on their lives. Women expressed anger at men being reluctant to discuss the situation and highlighted that they were keen to get help but despite their encouragement men refused to seek help. Women were concerned about the impact of ED on their partner's mood and suggested that delay in men seeking established barriers to communication and caused marital problems.

Women referred to the impact of ED on masculinity and used the term "manhood" when talking about the impact of ED on their partners although women did not appreciate the affect of ED on men in terms of its impact on self-esteem and confidence. In terms of identifying the problem women expressed that ED caused relationship problems, reluctance among men to seek help caused women to become upset and feel isolated. Women were concern about the possibility of underlying pathology. When discussing "the problem" most of the women I interviewed did not refer to ED or sex although ED treatment was considered to be false and without emotional attachment. Women acknowledged that "the problem" related to how ED affected their partners in terms of its impact on mood although women did not understand why ED caused men to become

withdrawn and to avoid communication about how ED affected them.

I identified six key categories or themes that emerged from coding the information I obtained from tape-recorded transcriptions of interviews with women. The following themes represented the main issues that women highlighted when talking about the impact of ED on their lives. All of the themes were connected by issues relating to communication.

**1. The nature of the problem**

**2. The impact of ED from the couple's perspective**

**3. Identifying the causes of ED**

**4. Barriers to seeking help**

**5. Deciding on treatment**

**6. The importance of communication (The Key Category)**

I have used the key themes as headings to present the results of the interviews I conducted with women and I have included quotes from transcriptions that relate to the key themes.

**1. The nature of the problem**

Women were more concerned about the consequences of ED in terms of its impact on the relationship and less concerned about the impact of ED on the sexual act. The following quotes from transcriptions relate to issues that caused upset for women. These data provided insight into the affect of ED from a woman's perspective. Accounts from women suggested that they were surprised that ED caused so much disruption to their lives and the problem was compounded by men's reluctance to seek help. Women were disappointed that their relationship was vulnerable. Women did not understand their partner's reluctance to seek help.

*“I was frustrated and angry..... if this was something that meant so much to him then why did he not get help so obviously it didn't mean that much to him but that's the way I started to feel”.*

*I was upset that he didn't... I mean after 30years...you would like to think that if there was an issue you would be able to resolve it and I always thought we were very close and we worked very hard for everything we have got or whatever and I couldn't understand this causing a barrier if you like”*

*“It was affecting all aspects of our life not just sexual the full aspect of our marriage was beginning to get affected you know?”*

*“It definitely affects his mood and his outlook” “He was getting more and more depressed but I must admit I was getting depressed myself but it was just that it was getting him down... his whole outlook has changed”*

*“I thought as well ....that we talked about everything previous in our lives whatever came up we discussed it and this was something that wasn't getting discussed because it was getting that he just didn't want to talk about it and that causes a barrier too because you're saying how can you resolve it if you don't talk about it”*

*“It's not necessarily the sexual actual act it's the coming together and the closeness of it” “Yes he had changed towards me....he lost confidence in himself and he couldn't approach me”*

*“And when I do have sexual feelings well he can't help me in any way .....but the*

*sexual feelings pass but at my age you don't get them a great deal" "I did at the beginning because I felt I'm 57yrs of age...yes and it was just taken away from me. "It was quite hard for me but as the years go by you know...you do start to get used to it."*

## *2. The impact of ED from the couple's perspective*

The following quotes from women provided information about how ED affected men and provided insight into how men cope with ED. The impact of ED on men upset women. Women considered that the delay in men seeking help was damaging to the relationship. Feedback from women provided valuable information about the impact of ED on the couple. Difference of opinion between women and their partners on the importance of sex is highlighted in these quotes.

*"I mean the only way its going to affect us is because of how he is and how he feels about it. Like for me, were it (sexual intercourse) never to happen again, I would miss it but not to the extent that he would miss it and it doesn't affect my feelings for him but he feels that it does. It's a confidence thing".*

*"He thought that he was less of a man and he didn't see the point in being here...I said I didn't marry you for the sex side of things....we married because we loved each other and that still remains...and is no different.....it's just that a part of the whole thing is missing".*

*"There's not a day goes by that he doesn't think about it and he ends up crying" "I try to tell him to just try and get on with his day but he can't"*

*"He always called me a nick name I felt close to him as it was something only we knew but he doesn't do that anymore it destroys me so much"*

*“Treatment?” “What do you mean treatment?” “Like to give him an erection.....No I haven’t thought about that”*

### *3. Identifying the cause of ED*

Women were unaware of the potential causes of ED and considered various possibilities including age, hormone deficiency and serious underlying pathology. Women also blamed themselves for being less attractive and considered the possibility that their partner was having an affair. Knowledge among women on the prevalence of ED was poor. Women looked for reasons as to why their partners experienced ED and made conclusions by comparing their partner's predicament with to situations that they believed related to their partner's circumstances.

*“I have a nephew that has diabetes and he’s had it since he was 8 years old and it doesn’t stop him (having sex)....I mean he’s not married but he goes out and he’s had relationships and all the rest of it so you think well what’s the difference?”*

*“I thought it was an age thing because they say men go through the menopause as well”*

*“I thought he might be transferred to the hospital to see what was wrong just with cancer and things like that”*

*“I actually said to him when he was getting frustrated to go and see the doctor because I couldn’t help him I said you need HRT but he denied it”*

*“I had a very vague notion that there was something wrong but I didn’t think that’s what it really was...I was expecting something to be wrong with him”*

*“I was more concerned about the problems that could be underlying”*

*“Obviously I think as a female having had a reasonably good sex life up until that point I started to take it personally and I started to think my goodness you know...what’s wrong here when I actually did ask if it was me and he said No..No I’m tired or you get all the usual reasons... maybe just not feeling 100% but as time went on and then we ran into the angina thing and we realised then that there had been a problem and that had been part of it.”*

*“No I think if he gets the all clear...there’s nothing really wrong with him... so I thought that it might just be an age thing”*

#### **4 Barriers to seeking help**

Women expressed that men withdrew from communication and avoided discussion about ED. Accounts from women identified that their husband’s attitude was a barrier to seeking help. GPs were largely considered to be unhelpful. Women wanted to help their partners and encouraged men to seek help but men did not respond. Women were upset by the lack of intimacy. Delay in seeking help was significant in terms of establishing barriers between women and their partners and women suggested that ED treatment might be incapable of overcoming these barriers.

*“It was the first thing I said to him....go and see the doctor and he said I don’t want to so I said but I can’t do nothing for you so go and see the doctor but he wouldn’t go”*

*“He kept worrying about it and keeping it to himself and that must have been really difficult, he wanted to scream because of the type of man he is I started to talk about it*

*he then started to give me bits of information he said it is frustrating....he has cried before its been so frustrating and embarrassing for him”*

*“Well I didn’t push him to go to the GP because there’s no point and he said it was ok that he would see about it but it was a bit of a disaster because as you know nothing ever came of it...I didn’t really want to push him so I left it again and I left it as long as I felt I could because it was getting to the stage now I feel its affecting me more than I thought it would”*

*“I think as well it’s not something even friends talk about...there’s six of us and we’re really close friends and we’re all different ages and there’s things that are said that are ok but other things that you just don’t talk about”*

*“We went to the doctor after that but then the GP wasn’t very good, he wasn’t very helpful so we waited another year and then went back to this new doctor and he was very helpful”*

*“But I’m kind of annoyed at the doctor or the doctor that he saw because he didn’t help or send him to someone that could help but maybe he was embarrassed or perhaps not but I realise they have only got a little knowledge about a lot of things when it’s a GP right?”*

*“The GP didn’t really give him the information he was looking for”*

### **5 Deciding on treatment**

Feedback from women suggested that treatment was not considered to be a priority. It

was highlighted by women that despite sex causing discomfort they were willing to accept their partners using treatment if it improved their partner's mood. Accounts from women highlighted that they were excluded from treatment decisions by their partners. Men believed that restoration of erectile function was necessary to solve the problem.

*“He would say I can't let you down although I was quite happy with the situation well not happy but I wasn't disappointed...it has never been a problem for me because I don't get much satisfaction due to the affect of the menopause”*

*“I've not thought about treatment”*

*“It doesn't affect me it's not affecting me physically but he is a lot happier not just because he managed to get an erection but the difference helped him in life as he was getting depressed and fed up you know?”*

*“I said to him he might get an erection with Viagra but I can't just turn my feelings on”*

*“He wanted to make sure that I was happy and he felt that this depended on his success when he attempted sexual intercourse but I don't get much satisfaction from intercourse but now our marriage is more relaxed and our whole life is back to normal”*

*“I was unaware he had seen his GP and I was only aware that he wanted treatment after he saw you” (this woman was upset that her husband didn't ask for her opinion on treatment)*

*“I was probably more concerned that he didn't have any ill effects from treatment”*

*“If he got Viagra does he go round with a hardon all the time because you hear these awful stories and you think.... oh god”*

### *6 The importance of communication*

Each of the key categories were explicitly connected to communication issues. Women became emotional when talking about the impact of ED on communication with their partners. Women expressed feeling isolated in terms of accessing help and this caused considerable upset and frustration. The following quotes emphasise that communication deficit caused conflict between women and their partners.

*“I wasn’t disappointed and I kept telling him that but he wasn’t listening or communicating.....he wanted to make sure that I was happy and he felt that this depended on whether he was able to have sexual intercourse”*

*“He said I’m not much use as a man, which was silly and I used to try and make light of it and say don’t worry about it you might fancy me tomorrow night because he used to lie awake and worry about it?”*

*“He’s not a weak person but I know that his mind works overtime and like as you say this is just going to have a knock on effect so even if everything was ok it doesn’t matter what you say to reassure him you’re left with a man that’s low”*

*“He just didn’t want to talk about it and how can you resolve it if you don’t talk about it?”*

*“I wanted to talk about it but there’s nothing they can do about it and that was the end of the matter I wasn’t thinking of medication I was thinking there must be something*

*out there that you can do”*

### **Comparing accounts from women and their partners**

Lack of communication between men with ED and their partners may have contributed to opinion among health professionals that ED is a male medical problem (Brock et al, 2007). Men that I interviewed highlighted that they were to “blame” for the consequences of ED and although men delayed seeking help they assumed responsibility for dealing with the problem. Women wanted to talk about the problems associated with ED whereas men avoided discussion and waited approximately 3 years before seeking help. Women became reluctant to ask their partners to seek help. Men believed that treatment was essential to restore their identity and improve relations with their partners. Interpretation among women of their partner’s reluctance to seek help varied. Women did not understand why men did not seek help. Feedback from interviews suggested that women and men made assumptions about how ED affected each other. Women thought men had lost sexual desire and men assumed that their partners would be receptive to treatment although feedback from women contested this notion. Women expressed that treatment was “false” as it initiated an erection without feeling or sexual desire whereas prior to commencing on treatment men did not consider the prosthetic nature of a drug induced erection. Men informed me that they had discussed ED and the problems it caused with their partners but women denied that men made an effort to discuss the impact of the problem with them.

Women accepted that ED was associated with the ageing process whereas men were vague about the impact of age on sexual function. Feedback from woman contradicted men’s opinions on severity of ED. Women suggested that their partners experienced less severe ED and were able to have intercourse whereas feedback from men identified

severe ED and men expressed that they were unable to have intercourse. Men identified that ED caused problems for their partners and often suggested that women were primarily concerned about the impact of ED on sexual relations and sexual satisfaction.

## **Chapter 5**

### **Reflexivity**

### **Introduction**

The literature review provided few articles written by men on reflexive enquiry into the influence of gender on research interviews although reflexivity is a common component of feminist research in terms of highlighting the affect of gender on outcomes from research interviews (Oakley, 1986; Stanley, 1990; Ramazanoglou, 1992; Stanley and Wise, 1993, p 30-43; Padfield and Procter, 1996; Hearn, 1998; Broom, Hand and Tovey, 2007). It has been suggested by feminist researchers that women are likely to provide more reliable and honest feedback if they are interviewed by a woman, as women are likely to share similar social experiences (Oakley, 1986; Ramazanoglou, 1992; Finch, 2004; Stanley and Wise, 1993, p 30-43; Ramazanoglou and Holland 2002). The quality of feedback from research interviews conducted by women with female participants however may be weakened by collusion (Christman, 1998). Interviews conducted by men with women, according to feminist opinion, are inevitably dominated by hegemonic masculine traits, which are thought to inhibit women from expressing their opinions (Oakley, 1986; Stanley and Wise 1993, p30-43; Finch, 2004).

The value of reflexive research has been questioned due to the subjective nature of the data obtained from reflexive social enquiry and it is thought that in order to be valid even the most reflexive of social studies should produce objective feedback (Lentin, 2005; Sandywell and Beer, 2005). The notion that the validity of data from reflexive enquiry is dependent on its objectivity has been challenged on the basis that all data is knowledge and is therefore valuable (Glaser 1978, Stanley, 1990; Glaser, 2001, p145).

In this chapter I discuss types of reflexivity and the significance of reflexive practice in terms of my research and I discuss the influence of gender dynamics on my research outcomes. I discuss my influence on research interviews, transcribing feedback from audio tape recordings and the influence of my values and beliefs on my interpretation of

transcriptions and when comparing feedback from interviews with women and their partners.

### Epistemological reflexivity

Epistemological reflexivity involves inquiry into the way in which the research question and study design affected the construction of the data (Bourdieu, 1991). I discuss formulation of the research question in chapter 1 and my study design in chapter 3.

### Methodological reflexivity

Hertz, (1997, p viii) described methodological reflexivity as “having an ongoing conversation about the research experience while living simultaneously in the moment”. Methodological reflexive enquiry is the process of deconstructing and analysing our own practice and making conclusions about its impact on the data (Ironsides, 2001; Ryan, 2005; Ryan, 2007).

### Personal reflexivity

Personal reflexivity in research terms involves reflexive enquiry by the researcher into the way in which the research has been influenced by his or her personal values, beliefs, political views, experiences, social identity and personal perceptions (Mauthner and Doucet, 2003, p 127; Carolan, 2003). Personal reflexivity also involves enquiry (by the researcher) into ways in which he or she has been influenced by the research (Finlay and Gough 2003, p 37-38; Humphreys, 2005). Reflexive enquiry is thought to occur “in the moment” (Hertz, 1997, p viii) although reflexive discussions throughout the course of my research were ongoing particularly when analysing feedback from transcriptions of interviews I conducted with women. I identified with Ryan’s (2005) “deconstruction of praxis”, as it explained the process of reflexive enquiry in terms of questioning theories I had formed from personal experience and clinical practice.

## **The influence of gender on qualitative research interviews**

Although there is evidence to suggest that all aspects of social research is affected by gender there are few studies that have looked at the influence of gender dynamics on the research outcomes of studies that included men conducting research interviews about sexual issues with women (Masters, Johnson and Kolodny, 1977; Bentler and Abramson, 1981; Callaway, 1992). When conducting interviews with women I identified with Kamler's (2001, p 112) theory of "relocating the personal" as my role changed from clinician to researcher. One to one research interviews with women was a new experience. My opinion on how women adjusted to living with ED changed during the course of my research. Women's descriptions of their experiences in relation to the impact of ED did not conform to what I had learned from clinical interviews. Gender influences difference of opinion on the way people view society and how best to conduct an empirical study on real life interactions (Oakley, 1986; Finch, 2004) I believe that although of opposite gender I may have shared similar opinions on social norms with the women I interviewed. For example my motivation to get married is likely to have been influenced by similar social principles to those that influenced the women I interviewed to marry their partners. All of the participants in my study were Caucasians and most were born and raised in Ayrshire.

The literature review revealed no qualitative studies that included a sample of women that were interviewed by a male researcher about sexual issues although it is unlikely that my experience would have been similar to the experience of another male researcher that conducted a similar study. My personal traits influenced my experience and the personal traits of the women and men that I interviewed affected my opinion of what happened during the research process and when analysing the data. When reflecting on the many

issues that made my research experience unique I recalled Glaser's (1992) opinion that all is data and that all research should be considered valuable.

Gender may have influenced reluctance among the women I interviewed to disclose information about their sex lives although they did not avoid answering questions about sex. Perhaps the women I interviewed would have been more comfortable open about discussing sexual issues with a woman. Women may have decided that being of the same gender as their partners I inevitably colluded with their partners when interviewing them prior to recruiting them into the study. Perhaps collusion is inevitable when a man interviews another man about a sexual problem. The opinions of feminist researchers that data from research interviews conducted by women with women is inevitably more valuable than data from research interviews with women conducted by men (Oakley, 1986; Stanley and Wise, 1993, p 30-43; Finch, 2004) may indeed be accurate and may apply to research interviews conducted by men with male participants. It is reasonable to suggest that men may assume that a man is more likely to understand and agree with their opinions about their experiences than a woman. However the literature review did not reveal any studies or reports by men that were conclusive in supporting this theory. Feminist research is based on the concept of woman, which is the central concept of feminist theory (Alcoff, 1989). Feminist opinion is predicated by re-evaluation of social theory and practice from a woman's perspective but as a concept its validity is compromised, as it is considered to be inherently biased (Callaway, 1981; Lather, 1986; Hammersley, 1994; Hammersley, 1995, p 6-8).

Fisher et al (2005a) reported that women empathised with their partners by suggesting that failure to get an erection "didn't matter". Empathic understanding, however, may be difficult to achieve if it involves understanding of how gender affects the process in

which we identify meaning that relates to issues that are pertinent to gender such as sexuality and sexual expression. Challenging feminist opinion on the influence of gender dynamics in an interview situation is difficult. Historically men have dominated western society (Helegeson, 1994; Hoffman, 2001; Lippa, 2001) therefore I am unable to fully understand what it is like to live in a society that is dominated by the opposite sex. My career has been dominated by women and although men often hold positions of authority in nursing the nursing hierarchy in my experience has been predominantly female. Women's dominance of men in nursing has been highlighted (Burt, 1998; McRae, 2003; Stephens, 2009) and it has been suggested that male nurses are often homosexual (Harding, 2007). Gender, perception of sexuality and stereotyping are likely to influence interactions, particularly in research situations where interview participants are influenced by first impressions (Harding, 2007; South University Nursing Recruitment, 2011). Women that refused to participate in my study may have been reluctant to be interviewed by a man or a male nurse. It has been reported that patients may be reluctant to discuss sexual issues with a therapist of "specific gender" (Glover and Wylie, 1999).

The British government claim to be negotiating issues of gender inequality yet suppression of women in the United Kingdom remains evident (Klima, 2001; Sowards and Renegar, 2004; Lloyd, 2010). It has been reported that the gender gap in terms of equal rights is widening (Batty, 2008; Pinker, 2008; Lloyd, 2010) and that gender inequality has a significant impact on how men and women function in society (Prakash, 1992; Coats and Feldman, 1996; Twenge, 1997; Venkatesh and Morris, 2000; Jackson et al, 2001; Sprecher and Toro-Morn, 2002). It is reasonable to suggest that society (influenced by lack of government commitment to establishing equal rights) has contributed to current trends in prescribing of ED treatment including opinion that ED is a male medical problem. The opinion expressed by Brock et al (2007) that couple

assessment is not feasible due to lack of time may be indirectly reinforced by government policy (Adam, 1999a). However assessment of ED from a couple's perspective may reveal that partners have different opinions on the impact of ED and its consequences.

John Gray, author of *Men are from Mars / Women are from Venus* (1992, Chapter 1) suggested that distinct differences between men and women are inherent and evident in the behaviours of infants albeit his opinions have been criticised due the absence of research based evidence to substantiate his claims (Goldman, 1994; Murphy, 2001; Wood, 2001; Steinhauer, 2006; Noonan, 2007). Gray (2002, p 112) reported that boys react differently to girls when faced with life's problems and suggested that boys often become aggressive or violent and are likely to blame others whereas girls react to problems by blaming themselves. Gray (1992, Chapter 3) explained that in later life men cope with adversity by retreating into "caves" and women attempt to solve problems by analysing their predicament and communicating with others. Although it has been reported that male behaviour includes taking action and finding solutions to problems (Spence, 1984) Gray's opinion ultimately rejects this notion. Similar opinion to Gray's has been reported in other articles (Brumberg, 1988; Bell, 1990; Bransen, 1992; Figert, 1995; Armstrong, 1999; Oinas, 2001; Johanson, Newburn and Macfarlane, 2002).

The women I interviewed attempted to communicate with their partners in order to solve the problem but they did not seek help as they did not know where to access help and they were reluctant to discuss the problem with their friends due to the personal nature of the problem. Although the women that participated in my study were upset about their predicament they believed that it was inappropriate to ask their GP or their partner's GP for help. Women are thought to be more intent on pleasing others, communicating, understanding feelings of others, exploring emotions and being understood (Spence,

1984). The women I interviewed expressed concern about their partners and were willing to compromise in terms of accepting treatment if it improved their partner's mood despite the prospect of treatment causing them discomfort or sexual pain.

Prior to conducting research interviews I had discussions with my supervisors about the difficulties associated with transferring my role from clinician to researcher. The women I interviewed expressed that interviews were therapeutic. I acted as a clinician in response to feedback from one of the women I interviewed and I believe that my actions were justified considering that the woman had a history of sexual pain and explained that her husband's ED had improved her quality of life. By counselling the couple I facilitated communication and I believed I helped the couple to negotiate the problem. I acted in accordance to my professional code of conduct (NMC, 2008). The woman I interviewed did not communicate to her husband that she was upset at the prospect of him commencing on ED treatment. He thought his wife supported his decision to seek treatment and his wife's silence reinforced his opinion that she was keen for him to commence treatment. If she had not agreed to be interviewed she may have endured sexual pain in order to please her husband.

The influence of gender on research interviews conducted by men with male participants has been discussed although there are few articles that provide reflexive accounts from men that have conducted research interviews with men (Schwalbe and Wolkomir, 2001; Oliffe and Mroz, 2005). One of the most comprehensive reflexive accounts by a male researcher that conducted research interviews with men was published by Jeff Hearn in 1998. Hearn interviewed men with a history of violence towards women and concluded that collusion with these men encouraged them to believe that violence towards women was acceptable. Hearn's conclusion may have been harsh but nevertheless his reflexive enquiry highlighted the potential risks associated with conducting one to one research

interviews when undertaking qualitative research and stressed that the influence of the researcher may of detriment to the research participants and others.

Hearn's intention was to learn more about why men were violent towards women in an attempt to help women that were abused by men and highlighted that the prevalence of male dominance in heterosexual relationships is high. It is reasonable to suggest that dominant men with ED will seek erectogenic treatment regardless of their partner's opinion and it may be appropriate to consider that sexual abuse towards women by their partners is common (Sullivan and Bybee, 1999; Campbell, 2002; WHO, 2005) and may be facilitated by erectogenic treatment.

### **Defining normal sex**

Although there are many definitions in the literature of normal sexual function these are based on human physiology (Wessels et al, 1996; Schultz et al, 1999; Lue, 2000; Kandeel Koussa and Swerdloff 2001; Arcos, 2004). "Normal sex" is often defined in functional terms and definitions rarely include sexual behaviours (Levin, 1980; de Groat and Booth, 1980; Meston and Frohlich, 2000; Kandeel, Koussa and Swerdloff, 2001; Berman and Bassuk, 2001; Costa and Virag, 2009). The literature review revealed limited information on "normal sexual activity" from a relationship, cultural and psychological perspective. Perhaps the spectrum of "normal" sexual parameters is too broad when all of these factors are considered or maybe it is presumptuous to assume that "normal" in terms of sexual interaction and sexual expression actually exists. Much of what is written about sex is found in the popular press, in magazines and on the internet and although often unrealistic, these data influence public perception of normal sexual activity and sexual function (Katz and Marshall, 2004; Conrad and Leiter, 2004).

Treatment for ED has increased awareness of male sexual problems and although the women I interviewed associated ED with age, men were not convinced that ED was directly associated with the ageing process. Only 3 of the men I interviewed were under 50. Feedback from men suggested that they were unaware of the incidence of ED. When conducting interviews women used the term “normal” in responses to my questions and assumed I knew what they meant. Being “normal” reassured men and women although uncertainty about what defined “normal” was evident in feedback from interviews with both partners.

Information from the literature review on the influence of personality, sexuality, age, appearance and class on research interviews was limited (Manderson, Bennett and Sutjahjo, 2006; Hammond, 2009). Plummer’s (1995) book on “sexual stories” is one of the few publications that included reflexive enquiry into research involving sexual practice. Subsequent to highlighting the dearth in knowledge about sex and sexual activity, Plummer (1995) recommended that when researching sexual function, sexual activity and sexual relationships, the researcher should assume responsibility for responding to private sexual stories by “bringing these stories into public view”. Plummer (1995) suggested that the researcher is accountable for explaining in detail the sexual narratives that are produced from interviews about sex.

### **Barriers to communication**

It has been reported that health professionals avoid initiating discussion about sexual problems due to time constraint and lack of knowledge on how to deal with sexual disorders (Gott, Hinchliff and Galena, 2004). Health professionals have admitted to being embarrassed about discussing sexual issues with patients of opposite gender, ethnic minority groups, older patients, and patients that were known to be homosexual or

lesbian (Humphrey and Nazareth, 2001; Gott, Hinchliff and Galena, 2004; Hinchliffe, Gott and Galena, 2005).

It has been reported that the nurse's uniform encourages interaction with patients although it has also been labelled authoritarian and sexist and it has been identified as a barrier to communication (Nightingale, 1983; Holden and Woods, 1988, p 238; O'Connor and Wright, 1990; Skorupski and Rea, 2006). Prior to recruiting women to participate in one to one interviews I conducted a literature review to obtain information on the influence of attire on communication during research interviews. Uniforms were not identified as having a significant influence on the outcome of discussions about sexual problems between patients and health professionals (Humphrey and Nazareth, 2001; Gott, Hinchliff and Galena, 2004; Hinchliffe, Gott and Galena, 2005). Studies that looked at the effect of the physician's dress style on the patient-physician relationship suggested patients' attitudes towards their physician were not influenced by the physician's attire (Neinstein, Stewart and Gordon, 1985; Menahem and Shvartzman, 1998). I wear theatre scrubs (blue tunic and trousers) when conducting clinical interviews.

I considered interim feedback from a study by NHS Scotland (2008) that looked at designing a national uniform for nurses and other hospital staff. The most popular choice of uniform design identified from staff responses to a national consultation on uniform specification was a unisex tunic and trousers. Staff and patients across NHS Scotland were asked to provide opinion on the tunic and trousers uniform by participating in focus group discussions. A cross-section of respondents were recruited on the basis of age, gender and socio-economic demographics. Focus group discussions were audio taped and transcribed to facilitate analysis. Feedback suggested that traditional uniforms were rejected by patients. Nurses' uniforms were thought to have little meaning to patients due

to confusion associated with colours in relation to the nature of staffing roles. The views of staff and patients from this study (NHS Scotland, 2008) influenced my opinion to wear a tunic and trousers (or theatre scrubs) when conducting research interviews. Other studies suggested that patients preferred male clinicians not to dress in a shirt and tie or casual wear (Neinstein, Stewart and Gordon, 1985).

My attire is likely to have reinforced to the women I interviewed that I was a nurse or a clinician and is unlikely to have communicated that my role was that of a researcher. All of the research participants were aware of my role and designation prior to agreeing to be included in the study. I communicated my role and designation to the participants by written information, verbal introduction and my professional role and designation was reinforced by my identity badge.

### **Study limitations**

I have been a clinician for nearly 30 years therefore I think like a clinician and my research was influenced by my clinical perspective. I provide counselling for couples with sexual problems and I have witnessed psychological trauma resulting from ED. I have actively lobbied the Scottish government to amend schedule 2 prescribing of ED treatment. I have formed opinions on the impact of ED and its treatment that are relevant to my research.

The literature review revealed gaps in knowledge that influenced my research question and study design. I highlighted that research into ED was biased towards the opinions of men and there were no qualitative studies that looked at ED from a couple's perspective by obtaining information on the impact of ED from couple samples. My research suggests that although men are reluctant to discuss the impact of ED with their partners the problems they experience are inextricably linked to how their partners react or might

react to ED. Without enquiring into the impact of ED from the couple's perspective the nature of the problem may not be identified and treatment may therefore be inappropriate. My research findings are limited in terms of challenging what we know about the impact of ED on women and their partners as I obtained feedback from a small population sample. Further research into the impact of ED on couples is required with larger population samples to support my research findings.

On reflection I believe that the information from the literature review on the impact on men may be largely irrelevant in terms of its influence on the predicament of the men I recruited into my study. I believe my research findings were limited by not conducting one to one interviews with men and analysing feedback using similar methods that I used to analyse feedback from interviews with women. It is reasonable to suggest that by conducting separate interviews with women and their partners and analysing feedback from transcriptions of tape recordings consistency in comparison of accounts from both partners on the impact of ED would have provided deeper insight how ED affects couples. I plan to conduct further research into the impact of ED on couples and I will use similar methods of data collection and data analysis to obtain, analyse and compare feedback from women and their partners.

It is difficult to be precise in terms of identifying the influence of gender on the feedback I obtained from interviews with women and their partners although it is highly likely that a similar study conducted by a female researcher with a similar group of women and their partners would have yielded alternative results and conclusions. My research findings and conclusions were influenced by my opinion and interpretation of the information I obtained from women and their partners and I provided an account of how gender influenced feedback from research interviews that was based on my perception of events.

My research was biased as I relied on my observation and my interpretation of meaning from interactions with women and their partners. Five of the women that participated in my study contacted me by telephone to thank me for helping them deal with the problems they highlighted during our discussion and on reflection I believe that scheduled follow up appointments or telephone discussions with all of the women and their partners would have added value to my research.

Reflecting on research interviews I perhaps found it difficult to assume the role of a researcher. It is highly likely that a person with a professional background specific to research would have adopted a different approach to interviewing women. I recall being sympathetic towards the women I interviewed, particularly when they displayed emotion. Perhaps being sympathetic towards the women I interviewed influenced feedback from interviews. My reaction to the emotion women displayed was perhaps influenced by my role as a nurse, my gender or my role as a man and the symbols that influenced my opinion on how men “should” behave in specific situations. By observing interactions in my social environment or in the environment in which I grew up I was taught to believe that “real” men do not display emotion and that it was acceptable for men to show sympathy towards a woman that was upset. Perhaps being sympathetic towards the women I interviewed communicated that I was “on their side” or perhaps they believed that I colluded with their husbands when I interviewed them prior to recruiting them into the study and that collusion was inevitably influenced by gender.

According to Glaser (2005) the researcher’s opinions on the data, regardless of whether it is biased, is an integral part of the research as it adds value to the data and neglects the concept that data is bound by the rules of good and bad. Although I appreciate Glaser’s opinion my ability to empathise with the women I interviewed was compromised by my

gender as I am unable to see the world through the eyes of a woman. It is highly likely that my interpretation of feedback from interviews with woman and their partners would have changed had I been born in another country and harboured different cultural values and beliefs.

My research did not provide detailed information on real life interactions between men with ED and their partners. I conducted separate interviews with women and their partners and compared accounts from each partner of the impact of ED on the couple's relationship. My research findings are limited in terms of applying my findings to other population samples due to geographic location of the study and the small number of research participants. My research was specific to heterosexual, working class, married couples. Most of the participants were over 50 years of age and religious denomination of the participants was limited to Church of Scotland or Roman Catholic. It is reasonable to suggest that information on the impact of ED from a younger population sample of women and their partners with different religious or cultural beliefs would be inconsistent with my research conclusions. Future research is required in order to gain insight into how ED affects other populations including homosexual couples and single men.

I am a 46 years old male, I am a competitive body-builder and I weigh about 16 and a half stones and it is highly likely that my gender, my choice of occupation, my stature or my size influenced the opinions of the women and men I interviewed. Had I been a female body-builder with green hair, tattoos and piercings I'm sure this image would have projected different meaning to the men and women that participated in my study and ultimately influenced feedback from research interviews. The symbols that we use to process meaning are often more discreet and more subtle aspects of our appearance may

influence others to form opinions about us although it is important as a researcher to recognise that such interactions are not only specific to participants in research interviews (Menahem and Shvartzman, 1998).

I relied on men that agreed to participate in my study to deliver information about the study to their partners. Perhaps an alternative method of recruiting women and their partners such as newspaper advertisements would have influenced my research outcomes. It was convenient for me to recruit women by asking men to convey the information to their partners.

## **Chapter 6**

### **Discussion**

#### **Introduction**

This chapter looks at the significance of my research in terms of how it relates to current opinion on assessment and treatment of ED. I then discuss my study design and research methods and look at the value of my research findings in terms of filling the gaps in

knowledge that were highlighted in chapter 2.

This chapter goes on to discuss the relevance of symbolic interactionist perspective to my research project and looks at the relationship between ED and masculinity. Potential action strategies that may encourage GPs and other health professionals to consider assessment and treatment of ED from a couple's perspective are highlighted and I discuss the possible consequences of current trends in prescribing of ED treatment. This chapter ends by looking at the influence of my research on my clinical practice and by identifying future studies that may provide additional information on how ED impact on the lives of women and their partners. .

### **Interpretation of results**

Heterosexual couple samples have been included in quantitative studies of ED and its treatment and it is evident from these studies (Meston and Derogatis 2002; Cayan et al, 2004; Wiegel, Meston and Rosen, 2005; Althof et al 2006; King et al, 2007; Farca et al, 2008; Cappelleri et al, 2008) and other studies (Rosen et al, 2006, Brock et al, 2007) that communication between men with ED and their partners is poor. These studies, however, provide limited insight into the real life issues that influence deterioration in communication between men with ED and their partners. Comparing accounts from women and their partners on the impact of ED identified conflicting opinions on the nature of the problem and how to solve it and disagreement between partners was also evident on issues such as severity of ED, seeking help and treatment. Men with ED expressed that embarrassment influenced their reluctance to discuss the problem with their partners and prevented them seeking help from their GP. When women and their partners communicated about the affect of ED on their relationship both partners often disregarded what was said and made assumptions about their partner's perception of the

problem and its impact on the relationship. Women believed they were less attractive and men believed that their partners experienced sexual frustration. Women highlighted that their partners advised them to go “elsewhere” or have sex with someone else in order to achieve sexual satisfaction.

Men professed to know how their partners would react to them commencing on erectogenic treatment although women’s accounts of the impact of ED on their lives disputed the opinions of their partners including opinion on treatment. Men sought erectogenic treatment regardless that their partners experienced discomfort. Women did not inform their partners that they experienced discomfort during sexual intercourse. Men identified that they experienced severe ED whereas women described less severe ED. These data were consistent with feedback from studies by Rosen et al (2006) and Chevret-Measson et al (2004) and indicate that opinion between women and their partners on sexual activity and sexual function is inconsistent. These data suggest that prescribing treatment for ED without thorough assessment from the couple’s perspective may be detrimental in terms of the couple’s relationship and may not be necessary. Future studies are required to understand why women and their partners provide conflicting opinions on sexual function and sexual activity. The women I interviewed agreed to compromise and accept ED treatment in order to obtain a better life.

Women formed opinions on their partner’s perception of how important it was to rectify the problems caused by ED. Women assumed that their partners delayed seeking help because they felt it was not important and men highlighted that their partners encouraged them to seek help but waited over 3 years to attend their GP. Women highlighted that ED weakened the relationship bond with their partners. Women were angry and upset that a sexual problem caused a rift between them and their partners. Women struggled to

understand why ED had affected their partner's ability to communicate with them. Men were concerned about the impact of ED on the relationship with their partners although they did not communicate these concerns.

In chapter 2 I cited many studies that looked at the impact of chronic disease on couples (Newsom and Schulz, 1998; Cliff and MacDonagh, 2000; Helder et al, 2002; Folkman and Moskowitz, 2004). Conclusions from these studies suggest that chronic illness has a significant impact on marital relationships and women cope less effectively than men if their partner has been diagnosed with a chronic illness. The literature review on the impact of chronic disease on married couples highlighted that chronic illness affects sexual relations and influences change in the roles of the couple within the relationship. Partners of men with chronic illness often assume the role of carer therefore men with chronic disease become reliant on their partners. Sexual relationships are likely to be influenced in these circumstances by role changes as men with chronic illness become patients and often rely on their partners providing care and financial support if they are unable to continue in employment. Studies on the impact of chronic disease on couples have assessed how couples adjust from a physical and mental perspective to living with chronic disease and coping strategies have been developed to help couples deal with the impact of chronic illness and its affect on the relationship (Cutrona, 1996; Mann et al, 1999; Berg et al, 2003). Couples that negotiate chronic illness together are thought to be better equipped when dealing with the consequences of the disease process (Cutrona, 1996; Mann et al, 1999; Berg et al, 2003; Berg and Upchurch, 2007). These data relate to feedback from the interviews I conducted with women and their partners.

Lack of communication on the impact of ED between women and their partners was significant in causing relationship problems and added to the anxiety experienced by

women. The quantity of research into the impact of chronic illness on marital relationships is vast when compared with research into how couples cope with the impact of ED. Specific criteria has been developed to measure the dyadic coping mechanisms that couples display when adjusting to the impact of chronic disease (Mann et al, 1999) yet there are no studies that have looked at how couples cope with ED therefore it may be inappropriate to suggest that women and their partners “cope” with ED and its consequences as the term specifically identifies levels of distress in relation to how people react to adversity. Research into how couples adjust to the impact of ED is required and would make interesting comparison with feedback from studies that measured the impact of chronic disease on couples.

Although research into the impact of chronic disease on couples is widely available there is limited information from these studies on the impact of chronic illness on sexual relationships (Anderson and Wolf, 1986). Research that includes information on the impact of chronic illness on sexual relations often applies to disease that affects sexual organs such as prostate cancer and breast cancer (Hannah et al, 1992; Andersen and Lamb, 1995). However ED is common in men with chronic illness (Eardley and Sethia, 2003, p 2-4). Studies have highlighted that sexual relations are compromised by chronic disease although provide limited suggestion on how to overcome sexual problems. Anderson and Wolf (1986) suggested that psychological “interventions” are required to “meet the sexual needs” of couples that are affected by chronic disease although chronic illness is likely to influence sexual problems of organic aetiology. Sexual dysfunction associated with chronic disease may influence similar relationship problems to the problems that were described by the couples that I interviewed.

It was suggested by Fisher et al (2005a) that women “wait for a signal of some kind from

their partners prior to starting a dialogue” about how to deal with ED and its consequences. My research findings contested these data. The women I interviewed attempted to discuss the problem with their partners and encouraged their partners to seek help. Men avoided discussion about ED and were reluctant to seek help due to embarrassment. This study also reported that women empathised with their partners to help them “cope with ED” by suggesting that failure to perform “didn’t matter”. The women I interviewed used similar phrase in an attempt to console their partners. Men expressed that attempts by their partners to console them made them more upset and emphasised feelings of inadequacy. Comparison of feedback from interviews with women and their partners suggested that empathy between partners on the impact of the problem was not achieved. Theoretical connections in the data in relation to empathic understanding between partners were weak which was emphasised by the relationship between the core variable (communication deficit) and the phenomenon of interest.

Fisher et al (2005a) reported that “over 80% of men with ED and partners of men with ED rated sex as playing a *somewhat to extremely* important role in their relationship”. Feedback from the interviews I conducted with women and their partners was consistent with these findings although accounts from women and their partners that participated in my study identified inconsistencies in relation to the reasons why sex was considered to be important. Men focussed on the relationship between sexual function and masculinity and expressed the belief that their partners were upset due being deprived of sexual pleasure. Women waited for men to seek help and were upset at their husband’s withdrawal from communication. Women explained that they felt isolated and lost hope of resolving the problem by communication with their partners. Women accepted treatment for ED due to the prospect of it improving communication, improving their partner’s mood and enhancing their quality of life. Men failed to realise that their

reluctance to communicate caused their partners significant distress.

### Symbolic interaction and sex

People's reluctance to talk about sex influences opinion on sexual norms to be formed by relying on feedback from our interactions with society, the media and the self (LaRossa and Reitzes, 1993). According to Blumer (1969) interactions about sex influence our development and understanding of our role in society. Gender influences expectation of how we are meant to behave (Peterson, 1987). Feedback from interviews with women and their partners identified that ED caused men to question their role in their marriage. Men expressed that sexual function defined their sexuality and was integral in terms of influencing their ability to function as a man. These data relate to the opinions expressed by Witt (2004) and Mahowald (2009) on the development and maintenance of self-concept that were highlighted in chapter 2 of this thesis.

The symbols that define meaning about sex develop from interactions that begin in childhood (LaRossa and Reitzes, 1993). We learn by observation that sex is difficult to talk about and as we grow into adolescence we garner information about sex by listening to sexual stories that are often exaggerated and we develop unrealistic perceptions of sexual norms. The media influences sexual expectations and our sexuality shapes our lives by influencing the way we dress, the social circles in which we mix, our everyday interactions, the relationships we develop and the role we play in society. Feedback from interviews with women revealed that ED caused women to question their role as woman. Women expressed that ED made them feel less feminine because they believed that ED was a sign that they had become unattractive to their partner and to the outside world.

### Assessment and treatment of ED

My inclusion criteria for this study specified that men experienced severe ED. I identified men with severe ED by IIEF assessment of erectile function and the men that I recruited into my study informed me that they did not obtain nocturnal and morning erections or erections on self stimulation or stimulation by their partners. All of the men informed me that they were unable to have sexual intercourse and most of the men avoided sexual activity therefore I assumed that accounts from women on the severity of ED would have been consistent with feedback I obtained from men. Women's accounts of their partner's erectile function suggested that men experienced less severe ED. One of the women I interviewed informed me that her partner did not experience ED and that she had a healthy sexual relationship with her husband. Women described having sexual activity with their partners including sexual intercourse and identified that their partners experienced inability to sustain an erection.

These data suggest that the nature of the problem may not be identified if assessment of ED is not considered from the couple's perspective. Facilitation of communication between couples or couple counselling may solve the problems that were identified by women and their partners. Women did not understand how ED affected their partners and men did not wish to discuss the problem. If women and their partners disagree on whether ED is evident couple counselling may be required to assess the reasons why their opinions differ. The women I interviewed were critical of how GPs responded to their partners requests for help. Women highlighted that GPs lacked knowledge on how to help their partners and expressed that GPs did not consider that ED caused distress. Women queried whether GPs were experienced in the field of sexual medicine and highlighted that time restriction in primary care was likely to influence "quick fix" prescribing of ED treatment. These data relate to the opinions expressed by Brock et al (2007).

The literature review (chapter 2) revealed that knowledge of ED and its treatment has been influenced by the results of quantitative studies that focussed on men. Quantitative research that included heterosexual couple samples provided limited insight into how ED affected women. Few studies have considered the impact of ED prior to treatment being commenced yet men in this study and others (Fisher et al, 2005a; Fisher et al, 2005b) often waited years before seeking help. It is reasonable to suggest that communication barriers that manifest in relation to ED may be difficult to overcome after years of living with its consequences.

Men were convinced that treatment for ED would solve the problems they experienced and often expressed unrealistic expectations of treatment success whereas women were less enthusiastic about treatment and in some cases were unaware of their partner's intention to commence of ED treatment. Women defined treatment success in terms of its influence on communication, intimacy and their partner's mood and highlighted that ED treatment influenced a prosthetic response or a "drug induced" erection. This information was consistent with the findings of Althof et al (1992). It is reasonable to suggest that the high incidence of treatment cessation that was highlighted in studies by Pryor and Redmond (2000) and in other studies (Madduri, 2001; Fagelman, Fagelman and Shabsigh, 2001) may be influenced by incomplete assessment of the problem and the exclusion of partners of men with ED from treatment decisions. The women I interviewed expressed anger at being excluded from decisions on treatment. Men accepted "blame" for ED and believed that they should "fix" the problem. .

Feedback from the interviews I conducted with women and their partners suggested that ED treatment was considered by men and GPs prior to conducting thorough assessment

of the problem. Research suggests that health professionals find it difficult to discuss sexual issues with patients (Hinchliffe, Gott and Galena, 2005) and feedback from the women and men I interviewed highlighted that men avoided seeking help because of embarrassment and apprehension at the prospect of admitting to someone else that their ability to function as a man had been compromised. Men expressed that admitting to ED emphasised feelings of inadequacy and were convinced that ED was temporary and that their sexual function would improve spontaneously. Seeking help reinforced to men that the problem was real. Men expressed that admitting to ED acknowledged physical deterioration and that ED was perhaps associated with the ageing process. Men highlighted age as a barrier to seeking help and considered the prospect of being “too old” to commence on erectogenic treatment.

#### Why is ED considered to be a male medical problem?

The media hype that accompanied the introduction of Viagra promoted recreational use of the drug and implied that ED was not a serious problem (Burton, 2001; Gresser and Gleiter, 2002; Lexchin, 2006). Reference to recreational use of Viagra and the prospect of demand for the drug influenced political debate on the whether new medical treatments for ED should be available on the NHS (Burton, 2001). Media reports suggested that costs to the NHS in terms of prescribing Viagra were likely to equate to approximately 25% of the NHS drug budget (Boseley, 1998) although it transpired that the predicted demand for ED treatment on the NHS was grossly inaccurate (Ashworth et al, 2002).

The launch of Viagra was strategic and precise with media coverage promoting it as a lifestyle drug and clinical studies focussing on the prospect of improving male sexual performance (Collier and Iheanacho, 2002; Angell, 2004). Media advice on “normal” sexual function (Mulhall, Levine and Jünemann 2006; Lexchin, 2006) may have

influenced unrealistic expectation of sexual function and sexual performance. Difference of opinion between men and their partners on sexual satisfaction (Chevret-Measson et al, 2004; Rosen et al, 2006) may be influenced by media advice on a “normal” erection (Lexchin, 2006). Defining “normal” erectile function in terms of “erection hardness” fails to consider the couple’s relationship and the value of intimacy and sexual expression (Claes et al, 2010). Feedback from the women I interviewed suggested that measuring treatment success extended beyond assessment of erection hardness. By conducting a qualitative study I was able to gain insight into how ED affects people’s lives and my research findings suggested that quantitative assessment of ED and its treatment does not consider real life consequences of ED in terms of its impact on couples.

The manipulative power of the pharmaceutical industry is vast and marketing strategies are carefully designed to be subtle in coercion (Hattenstone, 2003; Lexchin, 2006). Sports stars are employed to endorse PDE5 inhibitors creating the impression that ED is not exclusively influenced by age (Lexchin, 2006). Pharmaceutical companies are driven to maximum profit margins prior to expiration of drug patents (Beckerman-Rodau, 2002). It is reasonable to suggest that Pfizer’s attempt to reverse the British government’s decision on rationing of ED treatment was not influenced by their concern about the impact of ED on health (Mayor, 2004). Although Pfizer have officially acknowledged inconclusive results in terms of treatment efficacy in studies that assessed “Viagra for women” it has been suggested that limitations in design of these studies and flawed research methods may have produced inaccurate results (Rosen, 2010) which paves the way for further investigation into the use of PDE5 inhibitors in women. The “New View Campaign” provided valuable information on the attitudes of women towards medicalisation of female sexual function (Tiefer, 2001) and recently it was suggested that criteria for assessment of female sexual function is focussed on identifying “sexual disorders” when compromise may not be considered by women to be problematic

(Giraldi, 2010). The women I interviewed contemplated strategies to solve the problems they faced. Men withdrew from discussion with their partners and refused to seek help.

The NHS guidance on the treatment of ED neglects individual circumstances, promotes the notion that ED is not to be taken seriously and discriminates against the cause of ED by restricting NHS treatment to men with medical conditions that apply to a selected list (Adam, 1999b). The government guidance on the prescribing of medical treatment for ED identified acceptable and unacceptable ED and by doing so encouraged GPs to assess ED on the basis of criteria rather than focussing assessment on men and their partners. According to the government the impact of ED on the lives of women and their partners is irrelevant when compared to the potential cause of the problem. Advice contained in the NHS guidance document on “normal” frequency of sexual intercourse is condescending, uncongenial and dictatorial and is supported by a study that used impersonal and objective terms to measure sexual expression (Johnson et al, 1994, p 137-141).

#### The relationship between ED and masculinity

Whether used for recreational purposes, accessed from illegal or internet sources or prescribed on an NHS prescription, men use Viagra for similar reasons. Global sales of Viagra and the demand for other erectogenic treatments including Cialis and Levitra emphasises that sexual function is important to men (Rudolf and Bernstein, 2004; Wertheimer and Santella, 2005; Jackson et al, 2010)

Feedback from interviews with men revealed that the impact of ED on masculinity was associated with loss of confidence and low self esteem. Men were humiliated by sexual failure. The suggestion by Potts (2000) that men should adjust to ED by “becoming

differently inscribed” to allow for appreciation of “diverse pleasures beyond the phallus/penis” conflicts with the real life experiences of the men I interviewed. The prospect of relinquishing “the penis’s executive position in sex” and exploring sexual activities other than intercourse was not considered by the men that participated in my study.

Understanding the impact of ED on masculinity may only be realised by men that experience ED. The women I interviewed described their partner’s mood and its impact on their relationship. The information I obtained from women on the impact of ED on men identified that ED caused men significant disruption to their lives. Men confirmed that ED affected masculinity although interviews with men did not identify the significance of demasculinsation and the extent of the problem. The distress associated with ED caused long-term anxiety and distress for couples. It is reasonable to suggest that awareness campaigns and access to treatment would be readily available for other conditions with similar prevalence and similar affect on the lives of men and their partners. Studies on the impact of chronic disease on the quality of life of couple samples far outweighs the number of qualitative studies that have looked at the impact of ED (Miller and Bradbury, 1995; Cutrona, 1996; Mann et al, 1999; Berg et al, 2003; Berg and Upchurch, 2007).

### **Action strategies**

Restructuring of NHS services in England may provide incentives for GPs to learn more about ED as it would be cost effective to provide assessment and treatment of ED in primary care rather than referring patients to a hospital based specialist clinic. On 9<sup>th</sup> February 2011 the Scottish government reviewed schedule 2 prescribing of treatment for ED and amended the guidance on access to treatment for men with severe distress

(Strang, 2011). GPs can now prescribe ED treatment for men that experience severe distress resulting from ED. Although the amendment stipulates that the task of identifying severe distress in men with ED will be the responsibility of a secondary care “physician” or “surgeon” treatment will now be maintained by GPs in primary care and not from a hospital based clinic. The changes to schedule 2 prescribing of ED treatment in Scotland does not apply to other parts of the United Kingdom (Strang, 2011). Review of the NHS guidance on the prescribing of ED treatment in Scotland has influenced incentive among GPs to become more involved in assessment and treatment of ED. I have used this incentive to present my research findings to GPs throughout Scotland and these meetings will continue in 2012 and 2013.

My research findings have been added to a power-point presentation and are being used to educate local GPs and other health professionals on the importance of considering assessment of ED from a couple’s perspective. I plan to use my research to explain the benefits of couple assessment via local, national and international presentations and publications. I presented my research findings at the European Society of Sexual Medicine (ESSM) Congress meeting on 14<sup>th</sup> - 17<sup>th</sup> November 2010 in Malaga (Rutherford, 2010) (Appendix 3) and I also presented my research via oral and poster presentation in Glasgow at the World Congress for Sexual Health in June 12<sup>th</sup> – 16<sup>th</sup> 2011 (Appendix 4). Contesting the power of the government, the media and the pharmaceutical industry might be an impossible task although my research findings and future studies on the impact of ED on couples might persuade GPs and other health professionals to consider the benefits of assessing ED from a couple’s perspective. Plummer (1995) suggested that due to sex being such a personal phenomenon research on sexual issues should be published in the form of sexual stories. Although the media promotes the notion that ED is a male medical problem, sexual stories often stir media

interest and therefore the media may be used as a vehicle to challenge current trends in prescribing of ED treatment.

I plan to approach the Men's Health Forum to request assistance with a national campaign to promote thorough assessment of ED and other sexual problems.

### **Change in practice**

My approach to clinical interviews now focuses more on ED and other sexual problems from the couple's perspective. I encourage partners to attend my clinic and if they are reluctant to attend I encourage men to communicate with their partners, particularly when embarking on treatment. My research improved my understanding of how ED affects couples and I gained valuable knowledge of ED from a woman's perspective. My awareness of conflict of opinion between women and their partners on the nature of the problem and solving the problem has increased.

I am aware that assessment of ED from a couple's perspective may not always be possible although assessment of the couple may be important in terms of providing the correct advice. Prescribing of ED treatment will not always improve the couple's relationship. Knowledge of issues relating to partners of men with ED might be integral to achieving treatment success and may also influence treatment cessation. If couple assessment is not possible potential conflict in the opinion of ED and its treatment between men and their partners should be highlighted during clinical interviews.

I have been involved in lobbying the Scottish government to remove medical treatment for ED from schedule 2 prescribing since the introduction of the guidance in 1998. The government promotes shared care schemes and encourages multidisciplinary input into

delivering health care to the public yet the NHS guidance on prescribing of ED treatment is ambiguous and open to interpretation. The government's advice on "normal" frequency of sexual activity is at least ignorant and objectifies sexual interaction by suggesting that sexual activity is a measurable commodity. Accurate assessment of ED should be the primary objective of all clinicians when providing consultation for men with sexual problems regardless of time constraint. Information about ED in newspapers and in men's and women's magazines may encourage men to seek help.

### **Potential consequences of current trends in prescribing of ED treatment**

As the pharmaceutical industry develops new and more user friendly drugs to treat ED the line between medical therapy and maintenance or restoration of age related physiological impairment becomes less apparent. My research did not contest the notion that sex is a form of recreation. I believe that sexual activity is a healthy form of physical exercise. I struggled to understand the government's logic in their decision to exclude 70% of men from prescribing of ED treatment in primary care. I am not suggesting that recreational sex should be funded by the taxpayer but if drug treatment for ED has positive health implications then its availability on the NHS should be considered. Current trends in prescribing of ED treatment are likely to influence distress for men with ED and their partners due to lack of communication about the problem and its treatment.

The pharmaceutical industry has no binding affiliations with the British government and no legal obligations in terms of adhering to NHS policy, however, Pfizer Ltd were instrumental in shaping the Department of Health's political stance on the prescribing of ED treatment. The introduction of Viagra was the beginning of a new era in so called "life style" drugs and highlighted the lucrative potential of user friendly medical treatment for ED (Conrad, 2007, p 5). Although Pfizer used exploitative and

manipulative marketing strategies to promote Viagra, without the influence of the pharmaceutical industry lack of awareness of male sexual problems would have prevailed and a large number of men and their partners would have been destined to cope with the problem.

Rehabilitation of patients with mental illness and associated social phobia, in recent years, has been prioritised in terms of NHS funding (Ponniah and Hollon, 2008) yet the negative impact of ED on man's right to establish a relationship, to marry and have children and to die with his family at his bedside is not considered to be important perhaps because men are unlikely to complain about being denied access to ED treatment. It may seem extreme to consider these consequences as possible realities but if you are a man pause for a moment and think about the how ED would have impacted on your life.

Opposition to utilitarian ethics in health care has been reported to exist because of economic ignorance and unwillingness on ethical grounds among health professionals to embrace the thinking and techniques of the health economist (Mooney, 1992, p 90-98). Health economists, however, do not routinely treat men with ED or assume the task of explaining to men and their partners that they do not qualify for NHS treatment regardless of the impact of the problem on their lives. I believe that access to treatment for men with ED is largely influenced by GPs and it is unfortunate that the Department of Health neglected to consider that GPs are capable identifying men with ED that merit treatment on the NHS without having to refer to a list of conditions that excludes patients for no apparent reason (Adam, 1999b). Men with ED that have a condition that applies to the selected list qualify for treatment whether or not the listed condition has influenced ED.

## **Chapter 7**

### **Conclusions**

#### **Introduction**

This chapter looks at my research conclusions in relation to the key research question and highlights questions about the impact of ED on couples that were raised during the course of my research project. I provide opinion on the study design in relation to achieving my research objectives and compare the theoretical implication of my research with outcomes from other studies on ED and its consequences. This chapter then goes on

to discuss the need for future studies on the impact of ED. I then express my final thoughts on my research experience

My research produced valuable information on the affect of ED on men and their partners. The literature review raised questions about the impact of ED on men and their partners and these questions influenced my research question and study design. Qualitative study design was appropriate and as a clinician in the field of sexual medicine it allowed me to gain insight into the lives of women that have been affected by ED. My methods of data collection were thorough and methodical and analysing the data using grounded theory was an arduous task but worthwhile. Grounded theory provided the structure required to process the data and to make sense of the feedback I obtained from interviews. My research was justified by the knowledge my study produced on how couples react to ED and the problems they experience as a consequence of ED

### **Empirical findings**

Although it may seem that the impact of ED has been looked at extensively, studies have provided limited insight in to the impact of the problem from the couple's perspective.

My research findings identified significant difference of opinion between woman and their partners on the importance of sex and intimacy, the value of the relationship, communication about ED and its consequences and seeking help. My research suggested that conflicting opinions and lack of communication between women and their partners is likely to influence women's perception of treatment success. Communication barriers were established between women and their partners, which caused women to become isolated. Women were emotionally upset when discussing this. Barriers to communication between women and their partners were established through time (often

years) as men avoided seeking help. Women initially encouraged men to seek help and were willing to discuss the impact of the problem with their partners. Men expected their wives to be receptive to treatment despite excluding them from treatment decisions and disregarding encouragement from their partners to seek help. The long term effect of ED in terms of the disruption to the couple's relationship is difficult to predict and may prevail regardless of erectogenic treatment. Treatment for ED did not resolve the issues that the women I interviewed identified as being problematic.

In the introduction to this thesis I highlighted that my research question was influenced by gaps in the literature or lack of knowledge on the impact of ED on women. Subjective accounts from one to one interviews with women on the impact of ED produced new knowledge and deeper insight into the affect of ED on the lives of woman and their partners. Conflicting opinion on the problems associated with ED suggests that communication between women and their partners may change individual perspectives on the problem and how to solve it. It is reasonable to suggest that many of problems expressed by women and their partners may have been resolved had communication between been achieved. Men suggested that ED was "their" problem and although women wanted to solve the problem men were reluctant to seek help. Information from the literature review on the impact of ED on men is limited by lack of insight into the couple's perspective. The financial power of the pharmaceutical industry has dictated the research objectives of the studies that inform us about what is important in relation to ED and its treatment and the media influences opinion on "normal" sex. For over 20 years the pharmaceutical industry has assessed the value of chemical agents in the treatment of ED and neglected the impact of the problem on the lives of real people. Measuring erection "hardness" has little impact on the experiences of men with ED and their partners and disregards the social consequences of ED and its impact on a couple's

relationship.

Information from research interviews suggested that the problems men identified were influenced by their partner's opinion although men made assumptions about their partner's opinion without seeking clarification on whether their assumptions were accurate. Couples that participated in my study presented a unique set of circumstances in relation to the problems they experienced. In order to solve these problems it would have been imperative to consider these circumstances. This information suggests that the nature of the problem from the couple's perspective may not be identified if assessment of ED neglects to consider the opinions of both partners. Feedback from women highlighted that their partner's reluctance to communicate and apparent lack of interest in seeking help were significant in terms causing conflict within the relationship. The studies cited in the literature review (chapter 2) identified that men with ED presented with associated distress and depression although there were no detailed accounts of how ED and its associated problems influenced real life experiences of men including the impact of the problem on communication and how communication deficit affected couples (Seidman et al, 2001, MacDonagh, Porter and Ewings, 2002; Meyer et al 2003; MacDonagh et al 2004; Seftel, Sun and Swindle, 2004; Sand et al, 2008).

The women that participated in one to one interviews were highly motivated in terms of solving the problems associated with ED although through time they became reluctant to encourage their partners to seek help. Women believed that intimacy and sexual activity symbolised the emotional bond they shared with their partners. Men expressed that intimacy and sexual intercourse were part of the same phenomenon although they did not underestimate the value of intimacy. Due to their reluctance to communicate with their

partners and involve their partners in treatment decisions it appeared to women that sex was more important to men than the value of the relationship. Interviews with women and their partners provided a window of observation into the lives of the couples that participated in my study and these data are not representative or applicable to other population samples.

### **Theoretical implication of the research findings**

As a clinician in the field of sexual medicine I update my knowledge on a regular basis by reading journal articles and attending conferences. This research project changed my perspective on the information produced by research into ED and its treatment. Although it has been highlighted that ED affects masculinity understanding of how this phenomenon in terms of its influence on the lives of men with ED is poor (Sand et al, 2008). Feedback from the women I interviewed suggested that the impact of ED on masculinity affected both partners. Men that participated in my study believed that their ability to get an erection related to masculinity and their ability to function as a man.

It has been highlighted that partners of men with ED are excluded from assessment and treatment (Riley, 2008; Dean et al, 2008) but no studies have looked at the reasons why women are excluded. Research into the impact of chronic disease on couples considers the affect of chronic illness on the lives of both partners (Kiecolt-Glaser and Newton, 2001; Manne et al, 2004; Manne et al, 2005; Bodenmann, 2005; Berg and Upchurch, 2007). Studies of chronic disease and its impact on couples that neglect to obtain information from both partners are thought to be limited in terms of providing accurate information on real life scenarios (Bodenmann, 2005). Conversely it has been cited that it is acceptable to exclude women from assessment of ED despite sexual problems affecting both partners (Brock et al, 2007). Studies by Rosen et al (2006) and Chevret-

Measson et al (2004) found that women denied experiencing sexual problems regardless that their partners identified ED was affecting their sexual performance. These findings were consistent with my research outcomes and highlighted communication deficit between men with ED and their partners. People are reluctant to talk about sex (Stone and Levine, 1950; Peiss, 1986, p 244; D'Emilio and Freedman, 1988, p 428) and according to my research findings this includes married couples that have lived together for many years.

Restoration of erectile function may solve problems associated with ED for some couples although feedback from the couples I interviewed suggested that ED treatment may cause problems. Men that participated in my study did not consider that it was important to involve their partners when attempting to access erectogenic treatment. It was highlighted in feedback from interviews with women that drug induced erections were considered to be artificial and void of emotion and intimacy. It is important for GPs and other health professionals to be aware that women and their partners may not agree on the nature of the problem therefore treatment may not be directed at solving the problem from the couple's perspective.

The literature review revealed that GPs may obstruct access to treatment for ED (Sweeney, 1999). My research supported these findings. Feedback from the women I interviewed suggested that GPs lacked knowledge on assessment and treatment of ED whereas the literature review highlighted the GP's attitude may be important in terms of men gaining access to treatment.

My research produced knowledge on how ED affects couples. Conflicting opinions between women and their partners on ED and its consequences was significant in terms

of identifying the problem and dealing with the problems associated with ED. My research findings suggested that assessment of ED may produce inaccurate information on the nature of the problem and the value of treatment if the impact of ED is not considered from a couple's perspective.

### **Future work**

Future qualitative studies on the impact of ED are required to improve knowledge and understanding of how couples cope with ED. Marketing of ED treatment and clinical research into ED is biased towards heterosexual couples. Future studies on the impact of ED on homosexual couples is required to provide insight into how ED affects homosexual couples and feedback would make interesting comparison with my research findings. More independent studies into the affect of ED on couples are needed to provide unbiased information on the impact of ED prior to treatment being considered. It is highly likely that conducting one to one taped interviews with both partners and transcribing feedback would produce deeper insight into how couples adjust to living with ED. Research is required into the impact of ED on younger couples and future studies are required to gain deeper insight into the significance of conflicting opinion between men and their partners on the consequences of ED and its treatment.

Considering reports of sexual pain by partners of men with ED in studies that included couple samples further research is required to gain insight into the incidence of sexual pain among partners of men with ED and the significance of these findings (Chevret-Measson et al, 2004; Rosen et al, 2006).

### **Final thoughts**

The impact of ED on the lives of men and their partners is influenced by circumstance

and relationship dynamics, communication between partners, perceptions of what ED means to men and their partners and how men and their partners react to ED. The impact of ED on masculinity is well documented but poorly understood and the affect of ED on femininity has not been considered. Feedback from interviews with women and their partners suggested that men with ED were motivated to seek treatment to re-establish their sexual identity. Information from interviews suggested the impact of demasulinisation causes men significant distress and men might be motivated to commence on treatment to restore masculinity without considering their partner's opinion on treatment.

GPs should at least be aware that partner issues often dictate treatment success. Conflict in the data from the interviews I conducted on issues such as the nature of the problem, severity of ED and opinion on treatment were common. I did not expect such extreme differences of opinion between women and their partners. Considering the time GPs allocate to patient appointments, prescribing drug treatment for ED without involving partners might seem more resourceful.

Rationing of ED treatment is based on archetypal reasoning and is endorsed by political power. Attempting to change attitudes towards assessment and treatment of ED will ultimately challenge political perspective despite potential health and cost benefits. Medical therapy often improves organic function although ED might be caused by social factors, sexual incompatibility, relationship dynamics and psychological inhibition. Sexual problems are unique and each case merits holistic assessment. My research was limited in terms of observing real life phenomenon although feedback from women and their partners provided valuable insight into the impact of ED from a couple's perspective via accounts of events from both partners. Comparing accounts from interviews provided

valuable insight into the problems couples experienced and highlighted that due to lack of communication the nature of the problem was often defined on the basis of perception.

Feedback from my research suggested that women may have contributed to current trends in prescribing of ED treatment. Some women declined invitations to participate in research interviews and men avoided communicating with their partners, which influenced exclusion of women. Although couple assessment may not always be possible partners of men with ED should always be considered prior to prescribing erectogenic treatment although feedback from men is unlikely to be a true representation of their partner's thoughts on ED and its treatment. The amendment to schedule 2 prescribing of ED treatment in Scotland is an exciting prospect in terms of implementing change to prescribing of ED treatment by GPs. Allowing access to treatment for ED in primary care for men with severe distress may motivate GP's to become more involved in the assessment process, particularly if accurate assessment has the potential to be cost effective. I intend to offer GPs within my locality the opportunity to attend education meeting on assessment and treatment of ED and I will include data from my research to emphasise the value of assessing ED from a couple's perspective. The decision by the Scottish Government provides an ideal opportunity to implement an action strategy that will encourage GPs to consider partners of men with ED prior to prescribing ED treatment. Schedule 2 prescribing of ED treatment in England and Wales has not been amended.

My research was intended to obtain accounts from women and their partners on the impact of ED. Accounts of ED and its consequences were obtained from clinical interviews with men and structured one to one interviews with women and although data collection was by different routes my research findings provided valuable data and new knowledge on how ED affects the lives couples. By using qualitative research methodology to compare

feedback from interviews with women and their partners my research findings added insight into the impact of ED from a couple's perspective. I did not expect feedback from women and their partners to identify the reasons why ED is considered to be a male medical problem although my study provided information that identified potential factors that have contributed to current trends in prescribing of ED treatment.

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**Appendix 5** Examples of coding using grounded theory

## Appendix 1

### INFORMATION FOR PARTICIPANTS

Study Title: **Accounts of the impact of erectile dysfunction on heterosexual couples from men seeking erectogenic treatment and their partners**

**YOU ARE INVITED TO TAKE PART IN THIS RESEARCH STUDY THAT IS BEING CONDUCTED BY DEREK RUTHERFORD CONSULTANT NURSE FROM THE AYR HOSPITAL.**

Why is the study being carried out?

The purpose of this study is to obtain information on the effect of erectile dysfunction on women. Studies have looked at the impact of erectile dysfunction on men but there is little information about how women cope with the problem. The information we obtain from women will be compared with the information we get from their partners.

Why have I been invited to take part?

You have been invited to take part because your partner has been referred by his GP to Derek Rutherford's clinic with erectile dysfunction and he agreed to ask you if you would like to be involved in the study.

What will the study involve for me?

If you agree you will be interviewed by Derek Rutherford who is a specialist in sexual medicine. You will be interviewed on a one to one basis and the interview will be tape recorded. Tapes will not identify anyone by name and **confidentiality will be maintained at all times**. The interview room will be private although the topics that you discuss will include issues about erectile dysfunction. Your name will not be used at anytime.

What happens if you do not want to take part?

Your participation is entirely voluntary. You shouldn't feel under any pressure to take part. Your future treatment will not be affected should you decide not to participate. If at any time you feel unhappy about taking part in the study, you are free to withdraw from the study. If you withdraw from the study your future treatment will not be affected in any way. When being interviewed you can stop the interview at any time.

What if I have any questions about the study?

Derek Rutherford will answer any questions you have about this study **before, during and after the study.**

Derek Rutherford can be contacted on 01292 614528 or via switchboard at the Ayr hospital (01292 610555).

#### Confidentiality of information

Authorised representatives, the Ethics Committee and Regulatory Authorities may want to review your medical records to confirm accuracy of the information that is being collected. *Confidentiality will be maintained at all times.*

**Appendix 2**

**CONSENT FORM**

**STUDY TITLE: Accounts of the impact of erectile dysfunction on heterosexual couples from men seeking erectogenic treatment and their partners**

I confirm that Derek Rutherford has fully explained the nature and purpose of this 'Research Study' to me and has given me a copy of study information form.

I willingly agree to take part in this study and my partner is aware that I am participating in the study. I understand that I can drop out of the study at any time.

NAME OF PARTICIPANT (PLEASE PRINT)

.....

SIGNATURE OF PARTICIPANT

.....

DATE .....

I have explained the above study and have allowed the patient sufficient time to consider whether he wishes to take part.

NAME OF CHIEF INVESTIGATOR .....

SIGNATURE .....

DATE .....

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## Appendix 3

**INTRODUCTION:** Erectile Dysfunction (ED) is known to impact on the lives of men but few studies have sought to explore the impact of ED on women. Qualitative data on the perceptions of women and their partners on the impact of ED are limited.

**AIM:** The current research compared opinions and perceptions of women and their partners on the impact of ED by using qualitative research methodology. The aim of the study was to gain insight into this phenomenon.

**METHODS:** Men with ED\* were interviewed following GP referral and their partners were recruited via invitation to participate in semi-structured interviews. Consent was obtained from both partners. Recurring themes were identified from interviews with men and these data were compared and found to be in concordance with feedback from clinical audit and from the literature. Interviews with women were taped and recordings transcribed. Data were coded into categories using grounded theory methodology and categories were refined by identifying similar theoretical concepts. Interviews with women continued until the data had no impact on the theoretical relevance of the study (15 interviews). Emergent theory was tested by theoretical sampling and then compared with feedback from interviews with men.

**RESULTS:** Women expressed that ED consumed their partners and reported that their partners' perception of "solving the problem" focussed on restoration of erectile function. These data were verified by men. Women expressed that they attempted to confront "the problem" by encouraging their partners to seek help but became reluctant to pursue this action due to the reaction of their partners' to repeated suggestion. Women felt isolated and upset at the lack of reciprocity and struggled to make sense of their partner's perspective, as men communicated to women that the sexual act was of optimum importance in terms of defining their relationship. Men expressed concern that their partners might seek sexual activity "elsewhere" which reinforced perception among women that men defined the relationship in terms of sex. Women were concerned that ED was a symptom of a "more serious" underlying condition and felt helpless as men ignored their advice to seek help. Men often used the phrase "I no longer feel like a man" and expressed feeling "useless" and a "burden" to their partners. Women agreed with the prospect of treatment if it included "a health check" and if treatment was likely to improve their partner's mood.

**CONCLUSIONS;** Women were aggrieved and disappointed that ED had such a devastating influence on their relationship. The emotional trauma that women experienced and expressed suggested that feelings of hurt might prevail regardless of treatment outcomes. Women felt that their relationship was impregnable and were disappointed that their partners didn't seem to feel the same way. Men, however, expressed fear of "losing everything" and felt that restoration of erectile function would solve all of theirs and their partner's problems. Lack of communication between women and their partners influenced reliance on perception, which led to inaccurate and potentially damaging assumptions. These data do not provide solutions to the problems that couples experience when coping with ED but this study provides valuable insight into the perspectives of women and their partners on the impact of ED and emphasises that ED should be assessed from a couple perspective.

\* ED = <11 as measured by the International Index of Erectile Function.

13th Congress of the European Society for Sexual Medicine  
14 - 17 November 2010, Malaga, Spain

## Appendix 4

Dear Derek Rutherford,

Thank you for submitting an abstract to the 20th World Congress for Sexual Health scheduled to take place in Glasgow, UK, June 12-16, 2011.

On behalf of the Scientific Committee, we are pleased to inform you that your abstract A-354-0002-00043 entitled:

### **THE IMPACT OF ED ON WOMEN AND THEIR PARTNERS: QUALITATIVE ACCOUNTS FROM COUPLE SAMPLES.**

has been accepted for presentation. You will be informed at a later stage regarding the actual format of the abstract (oral, poster, narrated poster) as well as the scheduling details.

Please be so kind and advise us immediately, if you CANNOT present your abstract at the Congress, to e-mail: was@kenes.com.

If you have not yet registered and paid your registration fees you are requested to do so online via the following Congress website link:

<http://www2.kenes.com/was2011/reg/Pages/Registration.aspx>

The early registration rate is available until Thursday, March 31, 2011.

Accepted abstracts will be published in the Journal of Sexual Medicine (online and CD Rom), however only abstracts of presenting authors who have paid their registration fees by **April 11, 2011** will be printed.

We also encourage you to book your accommodation promptly, as availability may be limited in some hotels. Kenes has reserved many rooms of various categories at preferential rates. In order to benefit from these reduced rates you may make your bookings now via the Congress website:

[http://www2.kenes.com/was2011/acc/Pages/Hotel\\_Accommodation2.aspx](http://www2.kenes.com/was2011/acc/Pages/Hotel_Accommodation2.aspx)

Looking forward to meeting you in Glasgow.

Yours sincerely,

CONGRESS SECRETARIAT

## **THE IMPACT OF ED ON WOMEN AND THEIR PARTNERS: QUALITATIVE ACCOUNTS FROM COUPLE SAMPLES**

**D. Rutherford**

*Urology, NHS Ayrshire and Arran, Ayr, UK*

**Aim:** The current research was designed to gain insight into ED from a couple's perspective.

**Methods:** Men with ED\* were interviewed following GP referral and their partners were recruited via invitation to participate in semistructured interviews. Recurring themes were identified from interviews with men and these data were compared and found to be in concordance with feedback from the literature. Interviews with women were taped and transcribed. Data were coded using grounded theory and categories were refined by identifying similar theoretical concepts. Interviews with women continued until the data had no impact on the theoretical relevance of the study (15 interviews). Emergent theory was tested by theoretical sampling.

**Results:** Women expressed that ED consumed their partners. Men focussed on restoration of erectile function and these data were verified by men. Women encouraged their partners to seek help but men avoided help due to embarrassment. Women felt isolated and struggled to make sense of their partner's perspective. Men communicated that the sexual act was of optimum importance in terms of defining the relationship. Women were concerned that ED was a symptom of an underlying condition.

**Conclusions:** Women were disappointed that ED had such a devastating influence on the relationship and were upset at their partner's reaction to ED. Feedback from interviews suggested that feelings of hurt might prevail regardless of treatment outcomes. Men expressed that restoration of erectile function would solve all of theirs and their partner's problems.

\* ED 11 measured by the International Index of Erectile Function.

## **Appendix 5: Coding framework using grounded theory**

Open coding commenced with the 1<sup>st</sup> interview. I took notes during interviews to identify the meaning and context of rhetoric such as non-verbal communication, facial expression and emotions. All individual statements from transcriptions and additional notes were analysed and data was coded into groups of concepts until groups of similar data were established. Statements were repeatedly analysed, compared with new data, compared again and re-coded. The following is an example of analysing and coding a statement from a transcription.

**Statement:** *“I always thought we were very close and we worked very hard for everything we have got and I couldn’t understand why this caused a barrier if you like”.*

Written notes from the interview in relation to this statement included “is disappointed” “angry” “very emotional” “emphasising that she tried”, “distressed” “why”. Abbreviations were used to code the notes in order that notes identified with similar data e.g. anger was coded as an emotion and identified by the abbreviation EMT. Notes also included potential reasons why anger was expressed. I made a list to identify abbreviations. Line diagrams were used when writing notes to identify possible connections in the data. As data collection progressed although groups of concepts began to appear the data was often ambiguous and applicable to several groups. Data eventually settled in the group with the strongest theoretical connections.

## Coding Transcriptions

Capital letters were used in typed notes when analysing transcriptions (see typed notes in italics below) to identify groups of concepts, sub-categories and categories of data. Connections in the data were easier to identify when words that were relevant to groups of concepts were typed in capital letters. The following notes provide an example of what I mean by this: I have used the same statement as I used earlier.

**Statement:** *“I always thought we were very close and we worked very hard for everything we have got and I couldn’t understand why this caused a barrier if you like”.*

*It seems that she is emphasising strength in her RELATIONSHIP. The word “thought” may imply that she feels the RELATIONSHIP is threatened or has been weakened. “BARRIER” refers to COMMUNICATION but she does not elaborate and is not specific. It seems that INTIMACY has been avoided. “We worked very hard” implies that she feels she doesn’t deserve to be experiencing such ANXIETY but again she is not specific about what she feels is problematic. It seems she is saying that she has been through a lot with her husband and ED from her PERSPECTIVE is not significant enough to threaten the relationship (but it might be from his PERSPECTIVE). This statement communicates that ED is indeed causing RELATIONSHIP PROBLEMS and that her PERSPECTIVE on the situation differs from her husband’s. She may be angry with her husband. There is ANXIETY and DISTRESS in her statement and the notes taken during her interview confirm this. It*

*seems that she is asking for an EXPLANATION or she may be asking for HELP.*

Over 50 sub-categories and categories emerged from the groups of concepts prior to refining the data in terms of its theoretical relevance to the phenomenon. Categories were split into several relevant parts. As data collection progressed some categories became irrelevant and redundant. Highlighter pens, abbreviations, symbols and diagrams were used to code data with similar concepts. Data from transcriptions were also cut and pasted into similar groups using Microsoft word.

### **Axial coding/Key Categories**

Relationships between categories were established using a basic framework, which included the following elements: Phenomenon, causal conditions and context. From the above example “ANXIETY” and “DISTRESS” were identified as the phenomenon of interest. The primary causal condition was ED. Identifying explicit relationships between categories of concepts established causal conditions that were secondary to ED but of more relevance to the experiences that this woman described. Categories included lack of INTIMACY, poor COMMUNICATION and conflict in PERCEPTION of the impact ED had on the RELATIONSHIP.

Lack of INTIMACY was fuelled by poor COMMUNICATION at various levels and this was identified as a threat to stability in the RELATIONSHIP, which contributed to extreme ANXIETY and DISTRESS. The above statement indicated that there was poor UNDERSTANDING as to why ED caused COMMUNICATION “BARRIERS”, which was noted as a possible background (context) variable. This woman therefore

did not identify ED as “THE PROBLEM”. The cause of ANXIETY and DISTRESS related to all of the above categories. Notes were checked for other phenomenon of interest and the framework was applied to establish relationships in the data.

Identifying whether the women I interviewed were of the opinion that “THE PROBLEM” was directly related to ED was essential to UNDERSTANDING the phenomenon of interest and identifying the connections between ED and the causal conditions. Establishing the “Nature of the problem” was part of the process of attempting to identify and resolve the issues that women raised. Identifying causal relationships helped established a broad understanding of the connections between the data and the phenomenon. The framework helped define explicit theoretical connections between the data and the phenomenon and provided a structured process of developing the data into key categories.

*Nature of the problem* was identified as a key category from the above example of axial coding. The other key categories that emerged included:

- 2 Identifying the problem from the couple’s perspective**
- 3 Cause of ED**
- 4 Seeking help**
- 5 Treatment/Solving the problem**
- 6 Communication**

I now provide summaries of the process that I used to identify the other key categories.

***2. Identifying the problem from the couple’s perspective***

From open coding, categories emerged that contained concepts relating to PERCEPTIONS of ED. Other categories identified CONFLICT in OPINIONS between men and women. These concepts were connected to issues of COMMUNICATION, UNCERTAINTY and DISAPPOINTMENT that ED had such a significant impact on the RELATIONSHIP. ASSUMPTIONS about the impact of ED by men focussed on the PERCEPTION that restoring erectile function would fix THE PROBLEM. These data emphasised that COMMUNICATION about THE PROBLEM between women and their partners was poor. ASSUMPTIONS by women focussed on the RELATIONSHIP and the importance of sex in defining the RELATIONSHIP.

The following statement *“We were both fighting against each other whereas since seeking help (from the GP) we are trying to understand and work it out but we can communicate a lot better now.”*

Emphasised UNCERTAINTY and even after SEEKING HELP lack of UNDERSTANDING was evident. However SEEKING HELP may have provided a platform for this woman and her partner to agree on the NATURE OF THE PROBLEM and may have facilitated discussion about achieving a solution. The phenomenon of interest was the woman’s lack of UNDERSTANDING about THE PROBLEM. Explicit relationships were identified between categories including ASSUMPTIONS, UNCERTAINTY and PERCEPTIONS, which highlighted that causal conditions relating to lack of UNDERSTANDING involved issues that influenced avoidance of COMMUNICATION about THE PROBLEM and the importance of IDENTIFYING the NATURE OF THE PROBLEM from both

PERSPECTIVES prior to attempting to solve THE PROBLEM.

### ***3. Cause of ED***

The data clearly identified that women were excluded from assessment and treatment of ED. Categories of concepts from open coding highlighted that women lacked KNOWLEDGE on the possible CAUSES OF ED, which contributed to ANXIETY, and DISTRESS. Women that discussed the possible CAUSES OF ED with their husband's GP expressed poor awareness of causative factors. ANXIETY, DISTRESS and EMOTION in relation to the CAUSE OF ED was the phenomenon of interest. Causal conditions included PERCEPTIONS and ASSUMPTIONS by women about THE CAUSE of ED and lack of KNOWLEDGE on the incidence and aetiology of ED.

These statements are from 3 separate interviews with women:

***“Yes and we went through that as well. I'm sure it's perfectly normal to say well you don't fancy me.”***

***“I thought he fancied someone else.”***

***“At the time you don't think that it's normal.” “You start to examine yourself.”***

It was clear that ED influenced lack of CONFIDENCE and low SELF-ESTEEM among these women. They blamed themselves for THE PROBLEM. ***“At the time you don't think that it's normal”*** reinforces MISCONCEPTION about male sexual function. PERCEPTION that ED was not common influenced this woman's opinion that her husband had lost desire towards her and she blamed herself. ***“You don't fancy me”*** or PERCEIVED LOSS OF DESIRE was a manifestation of ED among women or a consequence of ED. Feedback from women identified that DISTRESS may have

been avoided if they had been aware of the incidence and the potential CAUSES of ED. Accusations that men had lost DESIRE put men under pressure to perform which influenced anxiety and increased the likelihood of failure. Failure reinforced PERCEPTION among women that men had lost sexual DESIRE.

#### ***4. Seeking help***

Issues surrounding women being involved in SEEKING HELP for ED created STRESS and ANXIETY. Emergent categories from open coding relating to these issues included notes and memos highlighting that women encouraged their husbands to seek help. As the study progressed the data suggested that women had BAD EXPERIENCES when encouraging men to SEEK HELP. Men with ED neglected encouragement from their partners to SEEK HELP. ANGER, APPREHENSION, ANXIETY and feelings of ISOLATION emerged into sub-categories and the phenomenon to which they related was the opinion among women that men's reluctance to SEEK HELP influenced lack of COMMUNICATION and influenced feelings of ISOLATION. The following statement highlights the FRUSTRATION this woman experienced when encouraging her husband to SEEK HELP. This woman experienced ISOLATION. Men expressed that embarrassment influenced their reluctance to SEEK HELP and the impact of ED on SELF ESTEEM and CONFIDENCE reduced their motivation to act. Men felt WORTHLESS and the impact of ED on MASCULINITY influenced feelings of uselessness, which caused them to withdraw from COMMUNICATION.

***“I asked him before and I asked him this time again because it had been such a***

*long time. I left it as long as I felt I could because it was getting to the stage now I feel it's affecting me more than I thought it would"*

Causal conditions were related to how men reacted to women encouraging them to SEEK HELP, which I identified as an active variable and also a background or context variable, as the BAD EXPERIENCES women reported were influenced by their partners. Men did not understand the consequences of their actions. Lack of COMMUNICATION influenced women to rely on their PERSPECTIVE which became their reality. The above categories that emerged from open coding identified with the BAD EXPERIENCE. Women highlighted and related to men expressing ANGER and NEGLECT towards them. The issues that women expressed in relation to SEEKING HELP emphasised lack of EMPATHY in terms of the impact ED on masculinity. This was enhanced by lack of COMMUNICATION.

##### ***5. Treatment/Solving the Problem***

Perception of THE PROBLEM among women related to the possibility of UNDERLYING DISEASE, ED and HORMONE DEFICIENCY. Women also highlighted issues concerning their husband's ability to cope with ED, the effect of ED on their husband's mood and the impact of ED on THE RELATIONSHIP. Medical TREATMENT for ED was not considered to be an important issue for women or women were less concerned about treatment than men. The data suggested that women had thought about SOLVING THE PROBLEM, which connected with other categories including IDENTIFYING THE PROBLEM and SEEKING HELP. Men made ASSUMPTIONS about the impact of ED on women and male

PERSPECTIVES on fixing THE PROBLEM almost exclusively involved restoration of erectile function. Women highlighted that SOLVING THE PROBLEM was more complex than quick fix medical therapy and attempted to COMMUNICATE their opinion to their partners with little success.

The phenomenon of interest in terms of SOLVING THE PROBLEM was CONFUSION. Women expressed FRUSTRATION, USELESSNESS and ISOLATION. Women felt HELPLESS as they failed in their attempts to SOLVE THE PROBLEM, which involved failure to COMMUNICATE with their partners. Active variables and the causal conditions were related to the key categories; NATURE OF THE PROBLEM and IDENTIFYING THE PROBLEM. EMOTIONAL TRAUMA expressed by women during interviews was influenced by the impact of ED on the RELATIONSHIP, lack of INTIMACY, apparent lack of sexual desire and reluctance among men to COMMUNICATE. Women were DISAPPOINTED that ED had such a disruptive affect on their RELATIONSHIP and this caused women to be UPSET and ANGRY. Men with ED did not seem to acknowledge that their partners were UPSET about their reluctance to COMMUNICATE.

Women and their husbands did not focus on THE PROBLEM from a couple's PERSPECTIVE therefore UNCERTAINTY about how to SOLVE THE PROBLEM was evident from the data and applicable to both partners. These data emphasised that men NEGLECTED their partners when attempting to SOLVE THE PROBLEM.

## ***6. Communication***

Axial coding identified that issues relating to COMMUNICATION had strong theoretical connections with all of the key categories. Examples of notes and memos from open coding of the following statements highlight that COMMUNICATION was an integral aspect of the NATURE OF THE PROBLEM and SOLVING THE PROBLEM.

*“I mean the only way its going to affect us is because of how he is and how he feels about it. Like for me, were it (sexual intercourse) never to happen again, I would miss it but not to the extent that he would miss it and it doesn’t affect my feelings for him but he feels that it does. It’s a confidence thing”.*

There is CONFLICT in this statement. It is clearly evident that COMMUNICATION is poor. THE PROBLEM seems to be influenced by PERCEPTION and MISTRUST as she highlights that he feels she is not being truthful. Similar scenarios were evident throughout interviews with men and women. Men did not believe that their partners placed less importance on the sexual act than other issues relating to the impact of ED. Men assumed that their partners made statements in order to make them feel better.

*“It definitely affects his mood and his outlook. He was getting more and more depressed but I must admit I was getting depressed myself but it was just that it was getting him down but his whole outlook has changed”*

His reaction to the problem affected her MOOD. Lack of COMMUNICATION was a major issue here.

*“Yes he had changed towards me. He lost confidence in himself. I don’t think he could approach me sexually. I don’t think he had the confidence. He did talk about it but not much”*

He can’t approach her sexually because he has lost CONFIDENCE but he avoids COMMUNICATING with her. She uses the word “think” indicating uncertainty. She reinforced that there was lack of COMMUNICATION by saying he did TALK but not much. What has she done about it? Would restoring his confidence solve the PROBLEM? How has he changed towards her? What is the significance of this? What does he think the problem is? He has lost CONFIDENCE.

*“I thought that we talked about everything previous in our lives. Whatever came up we discussed it and this was something that wasn’t getting discussed because he just didn’t want to talk about it and that causes a barrier because how can you resolve it if you don’t talk about it”*

She is FRUSTRATED and ANGRY. She “thought” they “TALKED” about everything. Is she questioning that now? He caused the barrier to COMMUNICATION. He didn’t want to TALK. She implies that COMMUNICATION may “resolve” THE PROBLEM. She is suggesting that CLOSENESS or INTIMACY is missing from their RELATIONSHIP. She implies that they both know that a PROBLEM exists but they are not INTIMATE so they do not TALK about it. What is her PROBLEM? Is the RELATIONSHIP threatened by the impact of ED?

The next statement was also included as an example in the key category “Seeking Help” and applied to concepts in other categories.

*“I asked him before and I asked him this time again because it had been such a long time. I left it as long as I felt I could because it was getting to the stage now I fee it’s affecting me more than I thought it would”*

She is willing to COMMUNICATE with him. He seems reluctant. It is causing her FRUSTRATION as she asked him to TALK previously and she asked him “again”. She has been affected by “it”. Lack of COMMUNICATION seems to be a major issue here and is beginning to become more PROBLEMATIC for this woman. Her PROBLEM may be solved if he was willing to COMMUNICATE.

### **The Core Category**

The relationships between active variables, context variables, and the phenomenon of interest from each of the key categories were explicitly connected to the issue of COMMUNICATION. Women identified lack of intimacy as a predominant cause of upset and distress. The NATURE OF THE PROBLEM according to women was largely influenced by the way men reacted to ED. Women emphasised that abstaining from the sexual act affected their husbands more than it affected them and the following statements from interviews with women confirm these findings.

#### **Example 1**

**DR “*Did you see this as being a problem from your point of view*”**

***Response: “No not from my point of view”***

#### **Example 2**

**DR “*Is the lack of sexual activity causing frustration for you?*”**

*Response: "I'm getting annoyed because he's getting annoyed whereas I still having the same sexual drive but I've always had a way of compensating for that I can have quite vivid dreams so I've got quite a good way of compensating round about that I do compensate round about that"*

Example 3

**DR** *"From your perspective what was annoying you about the situation?"*

*Response: "Just how it was affecting him"*

Example 4

**DR** *"He tried treatment and he responded...from your point of view what do you feel is the most successful aspect of the treatment?"*

*Response: "He feels so much better....you see it doesn't really affect me I get satisfaction in other ways but he doesn't"*

Example 5

**DR** *"You said that you had discussed the problem"*

*Response: "He would say I can't let you down although I was quite happy with the situation .....well not happy but I wasn't disappointed...it has never been a problem for me because I don't get much satisfaction (due to the affect of the*

*menopause)”*

Example 6

**DR** *“Were you reluctant to highlight the fact that there was a problem?”*

*Response: “For me the only way its going to affect us is because of how he is and how he feels about it....it doesn’t affect my feelings for him”*

These statements suggest that the women I interviewed did not consider the impact of ED on the sexual act to be problematic. However the following statements suggest that ED had a negative impact on their lives.

Example 1

**DR** *“And do you feel that treatment will restore what you have lost?”*

*Response: “It’s not necessarily the actual act it’s the coming together and the closeness of it”*

Example 2

**DR** *“And what your saying is that when you were watching him becoming depressed and worrying and being anxious that was making you worry and become anxious as well”*

*Response: “It was affecting all aspects of our life not just sexual the full aspect of our marriage was beginning to get affected you know?”*

Example 3

**DR** *“So you were worried about him?”*

*Response: “It definitely affected his mood and his outlook...he was getting more and more depressed but I must admit I was getting depressed myself but it was just that it was getting him down and his whole outlook has changed”*

Example 4

**DR** *“Did you have to encourage him to seek help?”*

*Response: “Yes”*

**DR** *“How did you feel about that”*

*Response: “A bit upset because he didn’t listen to me the first time when he should have went straight away”*

Example 5

**DR** *“You’re still young”*

*Response: “Yes and it was just taken away from me....it was quite hard for me but as the years go by you know you do start to adapt”*

Women became reluctant to encourage their partners to SEEK HELP, as it meant

acknowledging the problem, which caused friction and men sometimes reacted by becoming ANGRY resulting in further deterioration in COMMUNICATION.

The following transcriptions provide evidence of COMMUNICATION problems between women and their partners.

Example 1

**DR** *“Did he explain what he spoke to his GP about”*

**Response:** *“No”*

Example 2

**DR** *“And then did he seek help?”*

**Response:** *“It took him well over a year to go and see somebody about it”*

Her husband informed me that he had experienced ED for 6 months.

Example 3

**DR** *“And when he identified the problem were you aware there was something wrong?”*

**Response:** *“He’s not a weak person but I know that his mind works overtime and*

*like as you say this is just going to have a knock on effect so even if everything was ok it doesn't matter what you say to reassure him you're left with a man and he's low"*

**DR** *"Men often say that they seek help to please their partners because they believe that their partners are missing out on sex"*

**Response:** *"But has your wife said that?"*

This woman's husband experienced pain on ejaculation. He had a history of prostatitis and had been investigated by a urologist. He also experienced severe ED. He was reluctant to have sex because it was painful but he felt that his wife required sexual satisfaction. His attempts to have sex often ended in failure.

#### Example 4

**DR** *"For you it's something that's really been thrown upon you whereas he's obviously been to the GP and he's thought about it and been aware that the GP has made a referral"*

**Response:** *"I had a very vague notion that there was something wrong but I didn't think that's what it really was...he had changed towards me, I'm just trying to think how to put it into words, I don't know...he lost confidence in himself ....I don't think he could approach me sexually"*

#### Example 5

**DR** *"And when you mentioned that did he acknowledge that there was a problem or*

*was he aware there was but just didn't say anything?"*

*Response: "He acknowledged it as well"*

**DR** *"And had he been aware before that?"*

*Response: "No"*

**DR** *"No... so it was you that identified there was a problem with his erections?"*

*Response: "Yes"*

**DR** *"So was the GP helpful?"*

*Response: "He didn't really give him the information he was looking for"*

Men referred to TREATMENT as a "kick start" or used similar a term to emphasise that TREATMENT would only be used in the short term. There was reluctance among men to accept that THE PROBLEM might be permanent. Men referred to their sexual prowess when they were younger perhaps in an attempt to compensate for their feelings of inadequacy.

COMMUNICATION was the core variable and had powerful properties that connected with all of the key categories. Issues relating to COMMUNICATION were prolific in terms of connecting the causal conditions and active variables of the key categories.

### **Theoretical Sampling**

Theoretical sampling tested the connection between the theoretical concepts in the data and the phenomenon. The key categories were disassembled and the data was scattered into loose concepts. The concepts with strong theoretical connections to the core category were re-configured and the theory was tested by changing the relevance of its connection to the phenomenon. The theoretical relevance of the data to the phenomenon was analysed by retracing configurations of the data from the core variable back to the categories of concepts and open coding of the data. Theoretical sampling added another dimension to data by re-testing the connections between concepts and the phenomenon. Theoretical sampling acted as a means of validation. Theoretical sampling was flexible with no set pattern and data was fragmented and reassembled in various configurations to thoroughly test the relevance of theory to the phenomenon.