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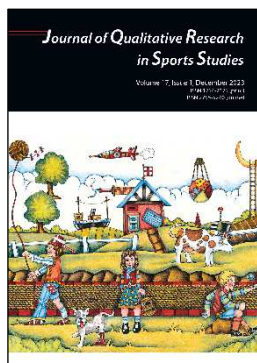
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# Traversing reflexivity in palliative care research: interpreting stress and anxiety

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## Abstract

This article explains how reflexivity was used in research by an Occupational Therapist (OT) with clinical experience of working with individuals in palliative care. Profession-specific reflections and interpretations of anxiety and stress are explored. An applied example of using 'reflexive triggers' from participants' data is set out, alongside diary entries that navigate the researcher forwards through the project. By means of honest accounting of 'lessons learned' to collect her data, light is shed upon some common concerns by qualitative researchers; such as about contaminating the data, or leading and influencing the participants, or whether sufficient depth of insight is gained by, in this instance, the use of telephone interviews versus (face-to-face) focus groups. The tensions between the OT in palliative care and the academic interests of the doctoral researcher are discussed in this clinical context. The article concludes that there has been a significant shift in interpretation and meaning of language surrounding the practice of OTs with a recommendation that clients' interpretations of anxiety and stress are to be valued.

## Introduction

### Different understandings of reflexivity

Reflexivity is essential within qualitative research to evidence validity, methodical process and conceptual reasoning, particularly within interpretivist research (Finlay and Gough, 2003; Darawsheh, 2014). Reflexivity is also critical to the audit trail within research, which Lincoln and Guba (1985, cited in Nowell *et al.*, 2017), and Finlay and Gough (2003:ix), defined as, 'being reflexive is to bend back upon oneself' complementing Etherington's (2004:19) interpretation of reflexivity:

To be reflexive we need to be aware of our personal responses and to be able to make choices about how to use them. We also need to be aware of the personal, social and cultural contexts in which we live and work and to understand how these impact on the ways we interpret the world.

Etherington (2004:32), whose background was also a community OT (similar to my own time as a clinician in the NHS), goes on to explain how researcher reflexivity 'closes the illusory gap between the researcher and researched by viewing

our relationship with participants as one of consultancy and collaboration', which is described as a 'bridge between research and practice that is essential to the argument' (Etherington, 2004:31). Although the broad use of reflexivity is well documented, the styles differ between Etherington (2004) and Finlay and Gough (2003). In Finlay and Gough's work (2003) they separate reflexivity into core tasks, one of which is to explore the reflexive triggers which influence one's research. It is these triggers I experimented with in my research, to demonstrate the connections between the transparency of the researcher (in terms of my influence and actions), and how this shaped my doctoral research with my supervisors acting as critical friends (Pywell, Roddam, Milston, Archer, 2017).

The researcher's journey can be framed in a variety of ways. Smith (2006:209) recommends use of both the 'realist' and 'confessional' approaches specific to OTs to maximise reflexivity and not unnecessarily expose, but constructively account for the researcher's decisions and choices throughout their research. Both approaches are valid, as only utilising a realist approach could be considered reductionist which limits the potential for reflexivity to excavate deeper understanding when used to its full potential (Conneeley, 2002:187). It was through 'bracketing', as described by Finlay (2011:23) that I was able to start 'pushing aside our habitual ways of perceiving the world'. In my doctoral research on anxiety and stress in the context of meaningful activities (occupations) and palliative care, I felt this was needed, but it was important to record how I did this and why, to embrace reflexivity and acknowledge potential biases, including cognitive biases, along this research path.

Specific to rigour, Smith (2006:210) argues that reflexivity can 'make the process more auditable, enhancing transparency of informal discussion, to make the research process more visible'. Smith (2006:214) goes on to contextualise researcher reflexivity as being essential to improve the 'quality of qualitative research in health and social care'. Lambert, Jomeen and McSherry (2010) argued the importance of using reflexivity for validation based on their extensive literature review of reflexivity in qualitative research for Midwifery. Unlike Lambert *et al.* (2010), Conneeley (2002) rejects validity within reflexivity as only having a place within quantitative research. However, while opinions are divided, validity is still called for in qualitative research (Taylor, 2017) so evidencing reflexivity, therefore, becomes a critical process within the research journey.

A reflexive journal, as described by Ballinger (2004:542) was used as a method to check for rigour or trustworthiness in qualitative research (Taylor, 2017). Smith (2006:210) successfully argued the purpose of reflexivity is to 'enhance future practice', but also warns us of not *just* walking through the steps of reflexivity, but to be effective with it. The reflexive strategy I used in my research was to complete a reflexive diary, filled with scribbles, drawing, colour and scraps of information I

gathered to connect my thoughts on the research and my emotions. This was my interpretivism in action, looking to understand the meaning within (Crotty, 2011). This scrapbook style could be likened to Smith's (2006:212) 'reflective log' and Conneeley's (2002:187) 'field diary'. It was primarily through these notes as diaries that I explored the research, being reflexive about the original reasons for choices and actions I made. This began with reflections on the clients I had worked with who had anxiety and stress, and my 'clinical self', wanting to be a better clinician.

Within clinical practice in the NHS, it was the experience of working with one individual in the community that had greatest impact on me, following a palliative prognosis of Motor Neurone Disease (Bulbar Palsy, a nasty, fast-progressing condition). They had declined speech aids from the speech and language therapist which fuelled part of this research. Their preference was to communicate issues and feelings through email, as speech and writing became physically tiring as the disease progressed. I can understand now that there is an aspect of increased privacy with these forms of communication. Emails have more characters than texting on phones or social media messages but still lack subtle cues and the opportunity to ask questions in a timely manner, unless the OT can respond immediately via a virtual conversation. I reflected upon the words that were used by this client and have wondered over the years if this form of communication was a familiar comfort zone for them, as perhaps used by work, and the communication of emotion was therefore done as if 'in work' format: very punctual, formal and to the point.

My reflections since were on what words were used and what I heard at the time. It is these reflections, complexities and challenges that the OT must rise to in order to facilitate best practice in communication. With clinical reflection, research and reflexivity, I continue to hear and learn more.

### **Research reflexivity versus clinical reflection**

Part of being an effective researcher is to grasp the differences between researcher reflexivity and clinical reflection, and where each has positively contributed to or influenced the other (Finlay and Gough, 2003). Both have a place in research. Etherington (2004) explores the differences between reflection and reflexivity, particularly in Occupational Therapy and counselling, as mere professional reflection may not encompass the many facets of researcher reflexivity. This raw perspective within reflexivity allowed me as a researcher to reflect on my part within the research, to take ownership and perhaps to identify why, if repeated, different researchers doing the same or similar research may have different perspectives. This article is therefore not merely a reflection but an in-depth reflexive stance on my research where I take full responsibility for the consequences of my decisions and actions as they have both added to and helped to develop the research to this level.

From my reflections as a clinical practitioner, anxiety and stress are experienced by many patients, but each experience, and articulation of it, is personal to the patient in the context of their occupations. Anxiety and stress do not restrict themselves solely to the diagnosed. They affect a person's occupations and are rife within palliative care. Anxiety and stress are immensely important to address and require advanced communication skills by the OT to do so. They are complex issues, often intertwined with facets of social, physical, mental and environmental concern and require the OT to look holistically at situations to address these complex and changing problems as the palliative condition progresses. Acknowledging that my clinical experience directly influenced my choice of research topic was an aspect of my reflexivity, for transparency, alongside accounting for my decisions and actions during the research. For instance, another researcher, one without any clinical experience, would likely approach this topic completely differently to me, and they would create their own reflexive account of research activity. Reflexivity, therefore, is the mirror - and the mirror's mirror.

### Reflexive triggers

Reflexive triggers, as described by Finlay and Gough (2003), were used to demonstrate validity of the data and transparency of this research process (see figure 1) which contains a selection of participants' responses and researcher's reflexive thoughts. This formed part of the 'audit trail for trustworthiness' (Nowell *et al.*, 2017:3). Reflexive triggers were captured under 'notes' within MAXQDA (software for thematic analysis of transcripts) during coding. Other reflexive triggers were captured within my research diaries. In essence, reflexivity, nebulous by nature, never stops and is only restricted by the researcher's project timeline.

**Figure 1.** Reflexive triggers: anonymised participant identifiers are P1, P2 etc.

Reflexive trigger	My thoughts
<b>P1:</b> 'I wouldn't directly ask a patient if they were anxious. I would perhaps say, you know, do you think perhaps there is something, you're a little bit frightened about or worried about rather than directly using the word anxious or stressed, because I feel that may limit the response.'	<p><i>This was fascinating. The first interview captured in the participants' words, that they wouldn't use the words anxiety or stress and reason why.</i></p> <p><i>Not every participant framed their reasons in this way but wow, this was a brilliant start.</i></p> <p><i>The dialogue flowed and at this point. it was where I had some regrets about not being able to ask them more, not having a conversation, but I was at that point of being so fearful of contaminating the data and really wanted to step back and try to be as removed from this as possible and not be seen as asking leading questions or influencing this.</i></p> <p><i>I could feel my confidence growing as a researcher.</i></p>

Reflexive trigger	My thoughts
<p><b>P2:</b> 'I think everybody has their own version of what they mean by anxiety and stress.'</p>	<p><i>This was very clear that common discourses are personal.</i></p> <p><i>Some of the participant statements were very, very clear on the point of individual interpretation.</i></p> <p><i>It was these nuances, these bits of information that when you collect them together, like bits of confetti, they become something beautiful.</i></p> <p><i>It was beautiful to start to see this, and to come back and see the clarified statements by participants.</i></p> <p><i>It made me proud to be an OT.</i></p> <p><i>They all communicated this passion for the individual's perspective and the individual's point of view and back to the other interview where they used 'their words' ....</i></p> <p><i>Coming back to this and connecting the dots again I can see this common thread of the strength and value and importance of individual interpretation.</i></p> <p><i>Additionally, the need to prepare OTs to navigate this and not see the potential interpretations as a negative thing, for there is potential to shy away from this.</i></p>
Reflexive trigger	My thoughts
<p><b>P3:</b> 'I think sometimes as healthcare professionals we fall into this trap of erm, er being, of having to deal with other quite highly qualified, well, sort of, highly experienced professionals, and it's quite hard to then sort of come back down to this more sort of, erm, easy to understand language.'</p>	<p><i>It made me think of not only how communication changes from being a newly qualified OT, to when you hit ten years in a workplace, to reflecting on what assumptions are made in conversations of emotion and what are the more 'easy to understand' terms and why.</i></p> <p><i>When I read more, I get a sense that this is connected to aspects of Fricker (2003) and social injustice... e.g. where it might, just might, be possible for a type of social injustice to exist.</i></p> <p><i>That is, where professionals intentionally or unintentionally use language or specific words around anxiety and stress, which did not connect, resonate with the patient and might even have an adverse effect.</i></p>

Reflexive trigger	My thoughts
<p><b>P4:</b> ‘I’ve seen lots of patients experiencing anxiety and stress and that can be related to their breathlessness or coming to terms with the different stages of their palliative illness journey.’</p>	<p><i>This was from a Macmillan specialist, again what I heard during and just after the interview was the clinical experience of seeing lots of patients with anxiety and stress was common.</i></p> <p><i>They connected this to breathlessness and points in time, or the ‘stages of the palliative illness journey’.</i></p> <p><i>The journey. Not a neat start and finish, but rather an individual journey is still a personal journey.</i></p> <p><i>Was I hearing exactly what they said?</i></p> <p><i>I felt a connection to the participant through the clinical experiences they reported. It felt like I was listening to a colleague in my team.</i></p> <p><i>Then I pulled back – was I supposed to ‘like’ some responses and not others in the research?</i></p> <p><i>How could I remain impartial and without judgement?</i></p> <p><i>Going back to these thoughts on the research helped connect the pathways of how I got from a to z, resulting in a greater transparency and trustworthiness.</i></p> <p><i>But was the reality I heard, the actual reality?</i></p> <p><i>Was I giving true justice to the participants (and the people they had worked with) through this exploration?</i></p> <p><i>I found myself being less clear than at the start.</i></p>
Reflexive trigger	My thoughts
<p><b>P5:</b> ‘It’s kind of a hidden subject, a taboo subject, and many people think of it, you know, if you say anxiety it’s a trendy word...’</p>	<p><i>I thought this was brilliant. I found this interview really rewarding to listen to.</i></p> <p><i>This participant provided many examples of how the meaning and interpretation of anxiety and stress could be different, and they were all things I could relate to.</i></p> <p><i>I wondered if more people saw and heard these things. Delving into the phrase ‘hidden subject’ made me look at the theme of invisibility and see multiple phrases across interviews applying to invisibility (the understanding of anxiety and stress as being invisible and the process of connecting meaning being invisible also). This became challenging during the iterations of coding as I built an argument in my head for nearly the entire code structure to fall within invisibility.</i></p> <p><i>Yet, on reflection, not all the codes fell comfortably within invisibility, and I added more justification and reasoning as to why within coding software.</i></p>



Reflexive trigger	My thoughts
<p><b>P6:</b> 'I think worry is again very much a layman's term that people would just think if a patient's worried that's very normal, but when you're getting into the realm of anxiety that's when it's becoming more of a clinical condition.'</p>	<p><i>This section of the interview really stuck with me.</i></p> <p><i>I couldn't believe how clearly the participant had separated the terms. This participant acknowledged working currently in the NHS and I couldn't help but connect my clinical experiences with this. Was there something in the way these terms are used within different health and social care systems? Do they mean different things to different professionals?</i></p> <p><i>Why is 'worry' not seen by some as an issue?</i></p> <p><i>From experience this can be how some articulate their emotional connection to the problem, but the problem still really affects their life hence the need to be seen by occupational therapy to unpick these reasons.</i></p> <p><i>But what is this? Is this my belief changing and affecting my interpretation of this research?</i></p> <p><i>(Looking back at the end of the research I felt at this point the need to embrace, tackle and go with the potential for political influencers of language, and for that to include the potential use of language within systems.</i></p> <p><i>This was also the trigger for considering Foucault (2002) and Fairclough's (1989) work, and my experiences from clinical practice.</i></p>

### Participants and their expectations of contributing to research

Within these diaries and utilising reflexive triggers, I saw other parts of the research differently. To begin with, the basic practicalities of doing, constructing, reporting and analysing the research can be viewed with a wider gaze thanks to reflexivity. Participant consent initially appeared as a very straightforward construct, yet now I see other things, particularly after reading Cohn and Lyons (2003). I was quite emotionally detached from the consent process and did not view it as a problem or with having problems, as I had not observed anyone sign the consent form, these were done on trust. It had not occurred to me until much later that participants knowing I was an OT, and also a postgraduate research 'student' conducting doctoral research, may have put them off consenting or altered their responses.

This is in line with the pragmatics of power and language imbalance (see Grice's principles 1975, in Archer *et al.*, 2012:47) where a speaker may expect a certain kind of response from a listener. As research participants, therefore, they may have assumed professional language was expected from them throughout their responses, as if in a test situation, and this may have altered the language they used - or could

have put them off completely from responding. As I was an OT and a researcher, both positions of relative power, I thought being 'detached' (not *leading*) was a good thing (the interviews being conducted by telephone), but I now acknowledge there was a lack of an emotional connection with the participants at the time, which might have otherwise brought about more candid and open responses if conducted face to face. As Wenger (2002:5) discusses in his *Communities of Practice*, 'having a genuine voice can be viewed as something that participants appreciate as it may promote openness in exchanges without necessarily losing professional language'.

The participant role as described in Cohn and Lyons (2003) indicates a symbiotic relationship whereby they may change their responses based on who they think the researcher is and what they think the researcher expects from them. This is a kind of Hawthorne Effect, a sense of 'giving the researcher what they want' attitude from the participant (Sedgwick and Greenwood, 2015). The only expectation I had was to encourage the participants to talk, so I guess when they were unable to answer questions in depth, I felt frustrated as I wanted the content of what they said to analyse. But my frustration was hidden as they couldn't see my facial expressions due telephone interviews. Reflexivity helped me to see the value of focus groups that came later in my research and not being afraid to be among participants and listening to the richness of discussion and debate.

### **The lone researcher**

The 'lone researcher' phenomenon is discussed by authors Etherington (2004) and Creswell (2018) from which I could see positive and negative perspectives of critique about my own research. For example, there are benefits to being part of a larger research team to collect data in different forms to shed light on an issue or topic such as 'patient experience', where employing those with different research specialisms in qualitative and quantitative techniques can be of great benefit. Conversely, as lone researcher, I managed the research design myself and took responsibility for data collection and its interpretation, but all the time accepting the limitations of it being solely my perspective on the data which in turn directed the research as a whole. For these reasons the practice of reflexivity by the researcher is very important, as it is for any research project (however methodologically aligned), helping the researcher to make discoveries from their data, direct their research, supporting their learning and ultimately in this health context, improve the quality of care and provision as a health professional.

'Lone-ness' as a doctoral researcher is a widely acknowledged concept (Tan, 2022; Sibai, Figueiredo and Ferreira, 2019; Cantor, 2020) which, in my case, was more to do with independence to lead my research (Gower, 2021), as I was not alone, and nor did I ever feel alone due to my generous research supervision. Interestingly, Conneeley (2002), although explicit about her reflexivity never wrote in her journal

article about being or feeling alone, perhaps as she was also working and researching in the same location. Therefore the idea of the 'lone researcher' could be considered just another interpretation of being involved with self-directed research. Smith and Palmer's (2015; 2021) research discusses being alone or being a lone entity on a mission to explore, which is not the same as loneliness, or being solitary (reclusive), and nor it is not the same as 'seeking solitude' which can often usefully lead to heightened sensory awareness and deeper critical moments in reflection.

### **Uncomfortable questions on stress and anxiety**

Reflexivity techniques helped me to explore the unexplored depths of the data from participants and my responses, given that my reflexivity notes became part of the overall stock of data for the whole project. An uncomfortable question for my professional reflection was, *'How might OTs make their clients' anxiety and stress worse?* In response, Participant 1 indicated that anxiety can be made worse by using the words 'anxiety' and/or 'stress', so I tried to stay clear of using both of those terms when I was with clients. To acknowledge this 'elephant in the room' was uncomfortable, yet, reflection on this perspective was needed to meet their needs.

No single definition of anxiety and stress is all-encompassing for the OT engaged in therapeutic communication with their client. Acknowledgement of this may prevent the assumption that everything is known within a conversation of anxiety and stress. OTs therefore need to reflect upon what may happen and what they need to be mindful of to navigate these interpretations in communication. This reinforces the idea that an individual's interpretation of anxiety and stress is significantly challenging for them as it relates to meaningful activity in palliative care. It is not possible to know how another person will define anxiety and stress or use these words until you ask them, so anything up to that point is an assumption. They may use and define anxiety and stress the same way you do, they may not. Just because you share one interpretation (e.g. anxiety with breathlessness) does not mean all other uses when framed with occupations and palliative care are the same.

When crossing this threshold of understanding, each term, every discussion about 'anxiety' and 'stress' and 'meaningful activity' becomes eye-opening within clinical reflection. Listening to the individual and understanding their meaning and interpretation of anxiety and stress is important to many types of clinical reasoning including narrative storytelling (Gunaratnam and Oliviere, 2009) and pragmatic clinical reasoning (Duncan, 2011). Despite the best of intentions, the semantic interpretation of anxiety and stress can be incorrect through assumptions which lead to misunderstandings (Archer *et al.*, 2012). Added to that, the individual may not stick to a definition either intentionally or unintentionally, depending upon their understanding of the terms. There is, therefore, potential for no single all-encompassing definition of anxiety and stress that suits every individual. This is a

paradoxical phenomenon of communicating about anxiety and stress in palliative care for the OT.

By being open to this potential for semantic misunderstanding, OTs may analyse and articulate these nuanced meanings through advanced communication skills (Wilkinson *et al.*, 2008; Turner, Payne and O'Brien, 2011; Brighton and Bristowe, 2016). By asking ourselves what we may have done, or what might have increased a patient's anxiety and/or stress, and what we would do differently are questions to change aspects of our practice, this being a critical piece of the puzzle within reflection by the OT. Thanks to the participants in this research, they have highlighted the potential for multiple interpretations of stress and anxiety which really do matter in clinical practice. It is the voices of experienced OTs connected with the evidence base from participants that confirms Etherington's (2004:32) conclusion that, 'When we enable other people (and ourselves) to give voice to our experience, those voices create a sense of power and authority'.

### **The transparent (but not invisible) researcher**

Absolute transparency of the researcher is said to enhance the reflexivity process (Etherington, 2004). Therefore, to 'contextualise myself' further as Etherington (2004:19) suggests, is to expose my emotions and unmask the researcher. As the researcher who never physically met any of the participants, I was initially invisible to them. However, in this article I hope to demonstrate my transparency as the researcher who was evolving, becoming visible and present in my research through reflexivity. Etherington (2004), although in anecdotal expert voice, has a pervasive argument about the use of 'I' when talking about one's reflexivity. In order to be transparent, but not invisible, I, am therefore going to use I throughout this section to add weight, volume and clarity to my thoughts. This section was surprisingly difficult to write, yet I have asked so many patients to talk about anxiety and stress without ever really considering it a difficult or onerous task in clinical practice. To put myself into this research I wondered how I would answer the questions. 'I', the OT, the researcher, the individual now and the future potential patient are separate individuals, separated by time, space and perspective, individuals who use different terminology. For instance, 'I' the OT would never swear as this would be unprofessional, yet 'I' as a person, a human being when anxious or stressed uses some swear words which I cannot bring myself to type in this article. Such a separation in language demarcates the patient and the professional 'I'.

I used terms included neither in clinical guidance nor in lists of medical definitions. To be honest, there are days where having studied this remit extensively, I still cannot clearly separate my personal definition(s) and use of anxiety and stress in my head – they are too complicated. Retrospective description of emotion is more useful to me, but as time has passed the emotional intensity seems to dilute which I

am never quite sure if I can truly capture and explain. This is one example of cognitive bias, fading effect bias, where negative emotions are forgotten more easily than positive ones. Surely, we need to reflect that in some ways, the expectations to clearly define emotional connections to occupation and their impact (when stressed or anxious) could be asking too much at the wrong moment? When, therefore, is the right moment to ask and get the answer? Thanks to this research, I am energised by the thought of ‘what is their interpretation?’, and ‘why didn’t they use the term anxiety or stress?’ When the term is present, it centres my mind on the client’s language preferences in communication of meaningful activities (occupations).

This researcher dilemma, I recorded in my diaries as personal preconceptions and assumptions of anxiety and stress, as Conneeley (2002:185) pointed out, ‘before putting pen to paper, I did not realise this [issue] existed’. Without reflexivity I would not have been able to write this. Yet still there is the gap, the gap we know to be between the demand for person-centred care and the realities of working in clinical practice. What anxiety and stress mean for each of us is personal, and at times very private. Mind this gap! The gap is whether we need to experience anxiety and / or stress to feel empathy and communicate successfully with our patients to help them through their journey, or is training enough? Initially within this research, and whilst I was in clinical practice doing this research, I thought the main reason for common discourses and different interpretations around anxiety and stress was negative. I thought this would require quite a straightforward approach to tackle it, which I realise now was mistaken. By using reflexivity, it is very clear now that this research is not the end, it is the beginning of a more sophisticated and complex understanding.

Acknowledging my ‘emotional involvement’ and how it ‘influences the research’ (Conneeley, 2002:187) is significant as my roles within the research required demonstrably separate perspectives on emotional constructs. My personal emotional opinion of anxiety and stress is separate to my professional emotional opinion as I can separate the two. Compartmentalisation of these emotions has been essential for me to practice in this context. The emotional opinion I have as a researcher is different again, and in my reflexive notes I explored my feelings about remaining ‘detached’ and not getting involved with a patient as a community OT would do. Rather, as researcher I was taking a step back to reflect on clinical practice; my experiences and from other qualified OTs, but also I was recognising my ethical role, boundaries and limitations ... protecting myself, them and the data.

Cognitive biases (Haselton *et al.*, 2015) align well with reflexivity here, for this is also about my own emotional journey and how this has affected my research. By doing telephone interviews it was possible to maintain a distance from the participants. Conneeley (2002), an OT who used similar data collection methods such as interviews and phenomenology, was explicit about how she used reflexivity

to improve transparency of her research, and therefore its trustworthiness and rigour. However, Conneeley (2002) was exposed in her role as the researcher as she worked in the same environment as the participants received treatment and conducted her research, something I had tried to avoid. I have in effect tried to stay somewhat hidden and separate, again through fear of influencing the results too much. Ironically, this behaviour still influences the research. Reflexivity ensures nothing escapes, and observations from all perspectives are identified and pursued.

### **Concern: data contamination in focus groups**

My main concern and reason for not doing focus groups initially was the risk of inadvertently affecting or influencing the language participants used either by my presence or the language I might use. Darawsheh (2014:562) refers to this as ‘contamination’. I initially saw this variable as having a negative impact including:

1. Would the group share and use a certain style of language because of their professional peers?
2. Would participants volunteer from a similar employer?

An alternative scenario is where I could have used focus groups, and been a part of the discussion, and revealed my own experiences as I am doing in this article, with the group. Smith (2006:213) describes how, as part of the reflexive process:

Revealing these tantalising snippets of selected personal information, all one was doing was encouraging the participants to reveal more of themselves and their thoughts.

This is a strong benefit I had not considered about my participation as a researcher in a focus group. I was worried I would influence or ‘contaminate’ the data through conversation and by my presence, or by accidentally asking leading questions. Perhaps my own voice, as the researcher asking questions over the phone was impersonal somehow, maybe a face-to-face interview with a cup of tea and biscuits may have elicited a different response? The benefits of doing focus groups are now clearer to me, as is being a part of them, revealing some of my thoughts and experiences about my background, or clinical experiences, can add positively to the quality of the research. My voice is both as a researcher and a qualified OT colleague. Through my reflexivity, I now understand my voice too has strength and weight within this research, although some may argue I cannot be my own participant, but I can be present and heard.

Telephone interviews allowed a positive space for participants to articulate their language use without immediate influence from others within a conversation, other than the researcher asking the questions. There are so many variables that would have influenced the participant’s use of language leading up to the telephone interview. These include culture, family, religion, spirituality, mood (and affect) to name but a few. Another scenario is where, if repeated, the interviewer could be a

different person to the researcher, i.e. there would perhaps be another level of separation between the participant and the researcher. Perception of the influence of an interviewer may have influenced results, as Cohn and Lyons (2003:42 citing Foucault, 1980) point out:

A 'power reflexive stance' takes reflexivity one step further by asking researchers to consider not only themselves as individuals but to consider the vector of power in all research interactions.

Power dynamics have impacted on this research, as with all research, and are weighty within this topic area as Smith (2006:213) has described, 'the webs of power that circulate within the research process'. This resonates with Conneeley (2002:185) who gave explicit examples of power in research including 'the way the respondents placed me in the research, the information that they chose to give and my subsequent interpretation of the data'. Cohn and Lyons (2003:42) in exploring power in interpretive research for OTs, reiterated the dangers of this power as 'the potential to oppress others, reproduce inequality, or minimise the perspective of others'. Acknowledging these impacts would increase the transparency of the research, particularly with regards to its interpretive nature and its results being derived from a relatively limited number of participants. These insights into power and influence I considered at the start of the research with Fairclough (1989) and Foucault (2002) informing my decisions in relation to the language participants used, that was instigated by me as researcher.

It could be argued that by stating the researcher was an OT in the participant information sheet initiated a power dynamic. Cohn and Lyons (2003) connected this as being a decision about the power a researcher has. However, conversely Smith (2006:214) has suggested that 'confessional tales may expose the nature of the relationship the researcher has with the participant, which may help redress the power balance between the two'. These researcher relationships and power dynamics are influential in communication during interpretive research and therefore require consideration through the phenomenon of reflexivity.

### **Prioritising interpretations of anxiety and stress: a fault in the system**

The different interpretations of anxiety and stress were all important to my research, however, prioritising their importance was a challenge impacting my data analysis i.e. the decisions I had to make about words and phrases to promote or relegate their importance in the research process. Placing these interpretations in a linear scale did not do justice to their inferred meaning simply from the perspective that anxiety and stress may be defined by the individual and their relationship with emotion and occupation at that point in time. To look at an individual's meaning, interpretation and occupational use of the words anxiety and stress is significantly time-consuming to do in detail, which were facets of how demanding the research

experience was, captured in my diary entries at the time. However, comprehending the potential impact stemming from insights to different interpretations of anxiety and stress were these strengthening notions of social power. This reflects research on power and ambiguous discourse within macro-systems discussed by Fairclough (1989), Foucault (2002) and Fricker (2003). For example, as a product of Western attitudes to medicine and health care, Benjamin (2012:337) argued that the prevailing medical model was constricting the potential of mental health care:

The system puts people in boxes, treats them as ‘problems to be fixed’ and ‘ticked from the list’... that is, from a more positivist, objectivist viewpoint, that a Western medicalised model / system adopts.

For individuals not meeting the criteria for support or care, that is, through the assessment of their symptoms they are deemed to be ‘stressed’ but not ‘anxious’, or vice versa, is a diagnostic fault within the assessment system where misinterpretations can occur. Fundamentally, the client’s need remains: their need to receive Occupational Therapy when they are struggling with emotional challenges impacting their occupations (Cooper, 2013).

Using the term ‘patient’, ‘service user’, ‘client’, or ‘individual’ is a power discourse within itself (Greenhalgh, 2017). An individual may use different words to describe an event of anxiety and stress at one point in time, within one occupation, using their understanding of the construct of anxiety and stress in their world, which is not incorrect, it is the individual’s interpretation and holds value. Deconstructing organisational or formal system definitions of anxiety and stress can create realignment possibilities where the problem is not the individual and the language they use, it’s the system, or part of it, which cannot accommodate the individual and their language discourse around anxiety and stress. It is this tension which may be the fault within the system. Formal service criteria terms, official definitions, may be limiting who ‘fits the criteria’ for care or treatment. If you guide individuals to plan their own care, you empower them. If you remove judgement within the system that anxiety is worse than stress or worry, or vice versa then there is refocus on occupations that are meaningful, promoting open conversations about what is happening, what is important and why. The supportive aim is ‘we are going on the therapeutic journey together’, led by the individual, not a fault in the system.

Acknowledging the potential existence for different interpretations around anxiety and stress could empower the OT’s and the clients’ communication by accepting real-world communication that includes individual interpretations and some ambiguous discourses. Yanow and Ybema (2009:39) argued that ‘what you see depends on where you stand: perspective is all when it comes to knowing and knowledge’. The reality is that systems are imperfect, and we hold imperfect understandings of our own and others’ constructs of anxiety and stress that can be



difficult for individuals requiring absolute and definite answers. This imperfect reality also contributes to the potential of ambiguities in communicating about anxiety and stress. Within formal systems, one can argue imperfections in definitions and understandings of anxiety and stress are in themselves, flaws. Therefore, interpretations of anxiety and stress in the context of occupations are not imperfections, but rather individual understandings and perspectives to be valued.

In recent years, communication challenges were exacerbated by the impacts of the COVID-19 pandemic on professional practice, and especially since this research was completed, suffice to say that the clinical world changed significantly due to the pandemic. With face masks hiding spoken and unspoken words, and periods of telehealth (video-calling clients) primarily due to national lockdowns, OTs continued to address client needs around anxiety, stress and occupations in palliative care (Pywell, 2021a). Clinicians anecdotally reported in a workshop at the Royal College of Occupational Therapists (Pywell, 2021b) that conversations had changed due to the increased worries of the pandemic. This made me reflect again on how much had changed during this research, and on what has potential to be a significant ‘meaning shift’ in communication (Le Fevre, Matheny and Kolt, 2010:726). This meaning shift will have inevitably altered clients’ descriptions, interpretations and understandings of their anxiety and stress, indicating that further, ongoing research is a constant necessity.

## **Conclusion**

Through the theory and application of reflexivity contextualised in this research, interpretations of anxiety and stress in palliative care have been explored through an OT’s lens. This experimentation with reflexivity has brought to the surface some valuable findings around researcher biases and impacts in this clinical context, especially the accounts of power imbalances and language use or interpretation, that are ever present in socio-cultural research.

The accounts and reflections offered in this article are beacons of how reflexivity can be conducted to guide the researcher through complex situations, focussing in on characteristics of social interaction and researcher decision making, and analysing their influences. We commend that a researcher’s qualitative data will be similarly enriched for the consciousness to become reflexive about comparable or related phenomena as they will be rewarded for the effort to observe, record and reflect upon their observations. Finally, we have emphasised the methodological importance of reflexivity in the clinical research process, for the benefit of the researcher, research findings, and ideally an improvement in the patients’ experience of receiving care.

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**Ethics statement:** This research was conducted with ethical approval from the University of Central Lancashire.

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## Reviewer Comments

**Reviewer 1:** This article, through a structured plan for reflexivity in research, exposes the tension between professional and research roles. It acknowledges and highlights the emotional complexity of working in the palliative care setting, and the weight that one carries both as a professional operating in this space, and even more so as a researcher. Navigating the responsibilities of both roles is explored without shying away from the difficult questions such as the immersion of the researcher, and conversely how visible the researcher is to others. The approach taken by the authors into the reflexive domain are valuable, particularly the discussion about the lone researcher which is sensitively unpacked, something that many would find comfort in and derive value from. Exposing personal thoughts about stress and anxiety in the public domain takes a moral courage that many researchers could also take note from, and for which the authors should be applauded.

**Reviewer 2:** This paper made me reflect on my own reflexivity and my work's impact on those whom it intends to help. The link of practitioners' use of language to social injustice really hit home as did many of the other points raised in this insightful paper. For example, divisions revealed through the use of common language; 'stress' and 'anxiety', as they may relate to the layman/patient versus the clinical professional, resonated with me greatly. The study made me appreciate the different perspectives these terms have for colleagues in my realm of sport; coaches, athletes, parents and administrators, and the loaded nature of these terms and labels. The use of the Reflexive Triggers framework provided a valuable and coordinated plan for reflexivity, demonstrating good qualitative rigor in the research process. A key part of this reflexivity was to become 'visible and present' in the research, and to acknowledge the 'power imbalances' in the conduct of research with participants. Although unpacked in this instance in the clinical setting of palliate care, the messages here are clear and easily generalisable to many other research contexts.