

SEXUAL EXPRESSION IN PERSONS LIVING WITH
DEMENTIA IN A NURSING HOME CONTEXT:
A PHENOMENOLOGICAL INQUIRY

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Abstract

Introduction: Research shows that sexual expression provides emotional and physical benefits throughout life and does not diminish with age or loss of capacity (Rennie et al. 2017). Older persons, living in care home, including people living with dementia see themselves as sexual beings and with a continuous need and desire to embody sexual expression. However, evidence demonstrates that sexual needs of 'residents' living in nursing or care homes are not viewed as an important part of nursing care (Bauer et al. 2013). Sexual expression is often overlooked as an important part of life in persons with dementia and is still considered the most difficult 'symptom' of the behavioural and psychological symptoms of dementia (BPSD) model to manage by nurses (Tucker 2010).

Aims and Objectives: This study aimed to generate new knowledge on the meaning of sexual expression in persons living with dementia for person-centred nursing practice and theory. This study also aimed to understand more about how sexual expression affects nurses working in care homes and how sexual expression influences the care of persons with dementia.

Methodology: Drawing on existential phenomenology, and person-centred theory as well as new principles drawn from the sensuous literature, I had conversations with four persons living with dementia to explore the nature and meaning of sexual expression. I was able to explore this sensitive topic in a dignified and respectful way by working with a rigorous process consent framework that enabled inclusion of adults with incapacity. I observed eleven nurses and carers and had dialogues with them at work to find out about their experiences of sexual expression within caring. Drawing on four existential principles, I was able to produce rich contextualised descriptions of the participant's experiences of sexual expression.

Findings: Findings show that for persons living with dementia, three topics were unconcealed within the phenomena of sexual expression. They were: (1) embodied sensuous-sexuality; (2) meaningful sexual relationships and (3) sexuality and nursing

home culture. For the nurses, findings show that the following topics were significant in nurses experiences of caring for persons living with dementia who express themselves sexually: (1) personal values and beliefs on older persons sexuality; (2) cultural norms around sensuous-sexual expression; (3) the ageing body and (4) lack of awareness and education. Finally, I have developed a 'Sensuous-Sexual Expression Framework', which is a new practice framework, and an alternative to BPSD, to view sensuous-sexual in persons living with dementia.

Conclusions: This is the first study to explore sexual expression which included persons living with dementia living in nursing homes and to gain valuable insights to their experiences of sexual expression. Practically, this study generates new principles for how nurses can provide better person-centred care for persons living with dementia. Academically, this research adds to existing research that challenges the BPSD model and its underpinning ideas and reframes sexual expression as sensuous-sexual expression.

Key words: Sexual expression; Persons living with dementia; Person-centredness; Sensuousness; Existential phenomenology; Participatory principles

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Chapter One: Introduction

Introduction

Throughout my professional career, it seems the topic of sexual expression in persons living with dementia receives very little positive attention from nursing and other healthcare professionals. Sexual expression in persons living with dementia has been a personal interest since I was a student nurse. My interest started when I was in my third year of my undergraduate degree, and I was on placement in an acute care environment. I was caring for a person living with dementia who expressed themselves in a sexual way towards me. This happened when I and a staff nurse working on the ward, was assisting the person with his personal care needs. It would be wrong for me to say that it did not catch me off guard, but what I remember vividly was the reaction from the registered nurse. The nurse started shouting at the person and was very unkind towards him. I felt that the reaction from the nurse was her response to feeling uneasy with the situation. I noticed that after this scenario, the care he received was poor as nurses would only approach him when necessary in fear of experiencing sexual expression. I have also experienced other example of sexual expression in persons living with dementia, which has resulted in poor care outcomes for the person receiving care. Additionally, I seen that it caused uncomfortableness for the nurses. Generally, it seemed to me that if a person expressed themselves in a way that is perceived as sexual by nursing staff, there is a high chance that the persons with dementia will be isolated from others, receive minimal care contact or even be prescribed antipsychotic medications.

In addition to being a full-time PhD candidate, I continue to contribute to clinical practice by working as a registered nurse in a nursing home in Edinburgh. In my clinical role, sexual expression is only discussed when there is an 'issue to manage'. 'Issues to manage' are usually when a person is expressing themselves in a sexual way in a communal area of the(ir) home, although I have seen that in some

scenarios even when the person is in their own private bedroom or bathroom, sexual expression is still classified as an 'issue to report'. Sometimes when older persons vocalise their sexual desires or make sexual comments, it gets written on a behavioural chart so that the 'issue' can be monitored and reported to the care home manager and general practitioner. Furthermore, there are concerns if two older persons, who are living in a nursing or care home, form an intimate relationship, which cause confusion and distress amongst staff and the older person's family members.

The care plans that I have been instructed to use in the nursing home have been modelled on the twelve activities of daily living (Roper et al. 1996). One of these activities of daily living is dedicated to 'expressing sexuality'. In this framework the nursing theorists claim that sexuality is relevant to nursing when considering the 'holistic' person (Roper et al. 1996), for then it becomes an integral aspect of being. However, in my experience it is often omitted or there is something written about physical appearance, for example, a man likes a shave every morning or a woman likes to wear red lipstick. As much as this is connected to how persons like to express themselves and that feeling comfortable and attractive is important to our sexuality, this does not go far enough in my view. Furthermore, I often see 'not applicable' put against sexuality care plans. I often ask myself the following questions:

- When does sexual expression become 'not applicable'?
- Who determines when sexual expression is 'not applicable'?
- If sexual expression is 'not applicable', why is this?
- Is sexual expression viewed as 'not applicable' in a nursing home because of a person's age, cognitive ability or where they live?

All these experiences has given me motivation to explore this topic further. My experience as a student nurse gave me the nudge to explore this topic for my undergraduate research dissertation and this opened my eyes to see that sexual expression in persons living with dementia is a phenomena which is often forgotten

about within nursing literature or viewed in a behaviouristic and problematic way, which I discuss further throughout this thesis. My time as a registered nurse has provided me with so many questions with regards to sexual expression and this research aims to begin to provide some answers. In my view, the need for sexual expression is as important for persons living with dementia as it is for so many of us. Of course, it is also a part of my life and my future, and in this thesis you will gain an insight into my philosophical beliefs about how all persons are sexual beings and how I believe our sexual expression has intrinsic value to life and wellbeing.

Sexuality and Ageing

For too long, the sexual desires and intimate connections of older persons have been swept under the carpet or have been subject to misunderstanding based on myths concerning a natural or inevitable non-sexual status (Zordan 2009). Contrary to wider beliefs, older persons have indicated how maintaining sexual expression can be an integral part of healthy ageing and perceived as a symbol of vitality and longevity, but that it is dependent on other physical health and wellbeing issues. Interestingly, according to Gewirtz-Meydan et al. (2019) and Malta (2007), some older persons do not consider older age as a preventative for a positive intimate life and sexual satisfaction.

Sexuality and intimacy are recognised globally as 'a central aspect of being human throughout life which encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction' (World Health Organisation (WHO) 2019). Despite that sexual expression is considered as an integral part of being a human being, DeLamaster and Moorman wrote that:

'if social scientists from an alien planet wished to learn about Earthling behaviour from reading our scientific literature, they might well conclude that sexuality is not important to humans older than 50.'

(2007 p. 921)

Ageist myths such as older adults are asexual, have led the general public, healthcare professionals and older adults themselves to believe that sexual expression, let alone sexual activity, is not for the aged (Syme et al. 2017). In contrast to pervasive stereotypes, the need for personal expression, physical closeness, intimacy, and sexual contact does not diminish with age or loss of capacity and continues to provide psychological and physical benefits throughout life (Syme et al. 2017). Often, healthcare professionals may assume older persons, especially persons living with dementia, may not be interested in romance, relationships or sex (Heath 2011). Nevertheless, nurses have a responsibility to support a person's sexual health and wellbeing, as sexual expression is a vital component in person-centred practice and of being a healthy person (Royal College of Nursing 2018).

In general terms, we continue to shy away from the sexual needs of older persons, and research that focuses on health problems and sexual dysfunction in later life encourages the stereotype that older persons do not, cannot, or are not interested in intimate sexual relationships (Maataoui et al. 2017). There has been an increasing, albeit still small, interest within academic literature on the importance of sexual satisfaction and intimate relationships regarding older persons including those living with dementia (Simpson et al. 2018; Drummond et al. 2013; Benbow and Beeston 2012; Yun et al. 2014; Gewirtz-Meydan et al. 2019; Malta 2007; Trudel et al. 2010; Loe 204). This small collection of literature has started to challenge the myth that sexual needs and desires diminish with age, and older persons are asexual and undesirable.

In recent times, there has also been an increase in the media concerning older persons and sexual expression, bringing it to the attention of the public. The sexual needs of older persons have made headlines in some of the biggest news broadcasting and magazine sources in the United Kingdom (UK). In 2015, the BBC news published a report all about the 'taboo of sex in care homes for older people'. This report highlighted that many older people wish to continue to be in an intimate relationship when moving into long-term care and end up missing close physical

contact with a partner (BBC News 2015). More recently, a health report was released, which headlined 'Majority of over-65s would like more sex,' (BBC News 2018). This article reported on a survey which showed that over half of people over the age of 65, feel they do not have enough sex and the same proportion of over-65s stated that one of the only reasons they would stop having sex would be a lack of opportunity. Similarly, the Telegraph, a national British daily broadsheet newspaper, has also published articles to publicise the importance of sex in later life. 'The truth about intimacy for older couples' (The Telegraph 2018) and 'Sex gets better with age say scientists' (The Telegraph 2012) are another couple of headlines that have marketed within the British media. While the evidence-base and validity behind these articles remains questionable and up for debate, there is no doubt that what gets published in newspapers and displayed on websites raises awareness, ignites public interest and conversations, and has the ability to challenge societal and cultural taboos.

When I was exploring what media coverage has been issued on sexual expression and older persons, I stumbled across the work of a Montreal-based photographer and filmmaker who wanted to challenge the belief that older people engaging in sexual activity is 'gross'. Malek states he wanted to show that older people having sex is a sensual and beautiful thing, and 'it's real' (Brenoff 2015). He set a scene for two volunteers (a man aged 92 and a woman aged 74), who wanted to show that older people still have sexual desires and crave passion within their lives. Malek claims that the reaction to the photo has been overwhelmingly positive and says 'It's a beautiful shot where we show something that really happens' (Brenoff 2015). He called the image 'The Photo That Proves Older People Having Sex is Beautiful' (*Figure 1*). I wanted to include this image within this chapter, as I believe it demonstrates sensuality, passion and sexual expression in a way that is rarely shown and challenges the myth around sex and older persons.

Figure 1: The Photo that Proves Older Persons Having Sex is Beautiful (Brenoff 2015)



Malek took great care in styling the photo. This is an incredibly rich photograph with a mix of various elements and messages. There is a humorous element with the couple's pet dog minding its own business and appears to be searching for something to chew on whilst the couple in the throes of passion. He set a dish of peppermints in the scene because he felt that peppermints were symbolic of being an older person and he always 'considered older people to carry peppermints with them' (Brenoff 2015). The artist also created the suggestion that even couples who have been together a long time can feel and experience sexual passion. This is represented in the photo frame that gets knocked over during the older couple's intimate moment. The photo also knocks over the more wholesome image of how an older person 'should' look and present themselves, according to society. Additionally, the lighting on the skin is incredibly rich and textured and shows off the contours of the ageing body in a very generous way. Despite the effects of

ageing being shown in the bodies of the older person, e.g. wrinkles, lentigines (age spots), this piece of art shows their skin in a glowing and sensitive light and conveys tenderness and intimacy, which is seldom captured in art, television, media, health or education.

Jean Malek has managed to capture an important message in his artwork, where he challenges the stereotypical thinking that society holds when it comes to older persons and sexual expression in a very sensual, tasteful and thought-provoking way. With the photographer's permission, I have used this photograph in many of my conference presentations and educational workshops when discussing sexual expression in older persons and persons living with dementia. Many of the participants in the workshops and members of the audience at conference presentations have approached me about this image saying that it is thought-provoking, and it communicates an important message about older persons and sexual expression. It is without doubt that the photograph leaves a strong impression on individuals and I aim to do the same with this thesis.

[Sexual Expression and Dementia](#)

Sexual expression with regards to older persons living with dementia is arguably a much more of a neglected topic. When it comes to sex and intimacy, older persons living with dementia have to face ageist stereotypes and myths suggesting that living with a cognitive impairment means being unable to give informed consent to sexual activity or even desire it. Sexual expression can be a concerning and problematic topic to address given the immense value placed on attributes such as memorising, forming judgements, and using problem-solving skills, all of which are characteristics that can decline with a dementia (Noguier et al. 2017). However, sexual expression is more than the desire for intimacy and sexual activity. It is the way persons communicate and present ourselves to the world as sexual beings. Sexual expression is connected to our personal identity, gender, bodily expressions and how we connect with others. Ultimately all expressions, and all bodily movement and activity is sexual in some part. Being sexual is intrinsically embedded in our very being and doing. So even talking about sexual expression as if it is merely

a component of who we are and what we do and one that can be isolated from others is an artificial proposition.

Due to what is medically diagnosed as disinhibition and disorientation, individuals living with dementia may express their sexual desires and needs in ways considered inappropriate by others. What is 'inappropriate' is highly subjective and could have different meanings depending on context and the individual. Examples of 'inappropriate' sexual expression could be overt expressions such as indecent exposure in public places, public masturbation, touching caregiver's breasts or genitals, obscene sex language and inappropriate propositions (Hayward et al. 2013; Tsatali and Tsolaki 2014). 'Inappropriate' sexual expression could also be a touch on the knee, someone standing or dancing closely to another, giving someone a wink or a flirtatious smile. Heath (1999) explains some of the possible reasons why persons living with dementia might express themselves sexually:

- With loss of short-term memory, the person with dementia may forget that they have recently had sex.
- A person with dementia may misrecognise and approach the wrong person in a sexual way.
- A person with latent homosexual desires may for the first time openly seek someone of the same sex
- A person who has experienced no or few partners may actively seek partners and obtain pleasures from the interaction.
- Reciprocity, an important aspect of any relationship, can be missing in persons with dementia.
- The partner of a person with dementia may no longer view them as a sexual partner, thus the person with dementia may seek to find intimacy elsewhere.
- A person with dementia may misjudge nursing care and nursing touch for sexual contact.

These examples are all fairly predictable. Reasons such as short-term memory loss or misrecognition give a sense of the breadth of reasons for sexual expression in healthcare settings. However, this list can also be said to be limited in several aspects. For example, sexual expression can be about sharing one's own identity and a sense of personhood, and it may be entirely consistent with how the person was or would have liked to be before the dementia.

Sexual expression of people living with dementia has also traditionally been categorised in negative ways. Terms with negative connotations such as, 'sexual disinhibition', 'inappropriate/improper sexual behaviour', 'sexual advances' and 'hypersexuality' are frequently being used to describe a person with dementia's sexual and intimacy needs. Here, I think it is important for me to state that I am not comfortable using these terminologies as they portray what are natural emotions and feelings as unnatural and problematic. I prefer the term 'sexual expression' as that it incorporates a more holistic and person-centred view of human sexuality. Therefore, whenever I use terminology other than 'sexual expression', I am doing so because that is how the authors are describing sexual expression within the existing literature. The definition of sexual expression that I will be using is an adapted version from the definition I used in my previous published literature review (Rennie et al. 2017). I define sexual expression as the following:

'Sexual expression is a general term used to describe the ways human beings communicate and present ourselves to the world as sexual beings. Our sexual expression is unique and includes the expression of our sexual thoughts, feelings, desires, senses, fears, hopes and dreams. Sexual expression is connected to all our ways of expressing sexual activity, intimacy needs, sexual orientation, identity and gender, bodily expressions and can range from how we move, walk and talk, how we relate to others and the extent to which humans connect with each other.'

(Adapted from Rennie et al. 2017)

Evidence emphasises that sexual expression is a fundamental human 'action' and can be an important aspect of wellbeing for all, including older adults living with dementia. However, this view does not seem to be recognised within dementia care policies and literature. In fact, persons living with dementia having, or indeed expressing, any form of sexual thoughts or desires fully epitomises the ageist assumptions around sexuality that some Western societies seem to have. Sexual expression in persons living with dementia is not considered a positive expression of who they are and their wellbeing but is usually met with negative interpretations and responses. For people living with dementia sexual expression is usually described pessimistically and viewed within healthcare as behaviour that needs to be minimised, controlled or even stopped all together.

'Sexual disinhibition' has been described as one of the 'symptoms' that form the behavioural and psychological symptoms of dementia (BPSD) model (Alagiakrishan et al. 2005). BPSD is an umbrella term for a heterogeneous set of behaviours and neuropsychiatric symptoms that the majority of people living with dementia are said will experience at some time during their illness (International Psychogeriatrics Association (IPA) 2015). A discussion document which emerged from the IPA conference on BPSD in 1996 claims that:

'Hypersexuality and sexual aggression are two behaviours that most clinicians would classify as behavioural disturbances of dementia.'

(Brännström 1996)

Since 1996, 'sexual disinhibition' is recognised globally as a behavioural symptom of dementia that can increase the likelihood of the person living with dementia to enter residential care (Onishi et al. 2006). There are various reports of the rates of 'inappropriate sexual behaviour' (ISB) according to the type and severity of dementia, with some suggesting there is no difference with respect to cognitive status or types of dementia and others suggesting that it is more common with moderate-severe dementia and more common with vascular dementia (Bardell et al. 2011; Alagiakrishan et al. 2005). What Bardell et al. (2011) discovered is that the

aetiology of 'ISB' remains unclear. Disruption of neural pathways with neurological insult has been suggested as playing a role in 'ISB'; however, this claim is without any evidence. There is limited empirical evidence regarding the efficacy of interventions aimed at reducing 'ISB' in older persons. Behavioural and environmental strategies such as redirection, distraction and sensory stimulation have been suggested, with reports indicating the reduction of ISB (Bardell et al. 2011.) In a retrospective chart review study, Bardell et al. (2011) explored the variables that may contribute to 'ISB'. Twenty participants were recruited from an inpatient geriatric psychiatry ward, ten people who were viewed as having 'ISB' (study group) and ten people who matched in age and gender (control group). Interestingly, this study could give no real significant conclusions other than it claims that 'ISB' was more likely to happen in people with more severe dementia. I suggest that the reason that this study and any other published literature can give no real conclusion on the aetiology of 'ISB' in persons living with dementia is because sexual expression is part of who we are as persons, and sexual needs is a dynamic part of life which varies across everyone and even the same individual across their lifespan. According to Tsatali et al. (2011), healthcare professionals view sexual expression as the most difficult symptom of the collection of BPSD to manage. The BPSD model, suggests that sexual expression is comprised of problematic behaviours that requires medication for control (Brodaty et al. 2003; Brodaty and Arasaratnam 2012). This again, implies that sexual expression is unnatural and people with dementia should not have any sexual or intimate feelings, or express them. In relation to healthcare, a major concern for persons with dementia is that it has been shown that individuals who express themselves sexually in front of or towards nursing staff receive poorer and less frequent care (Alagiakrishnan et al. 2005).

Focusing on a nursing home context, persons living with dementia, who move to live in a nursing or care home should be able to have the same rights, choices and responsibilities they enjoyed at home (Royal College of Nursing (RCN) 2018). In the UK, the terms 'care home' and 'nursing home' is often used interchangeably. Both

nursing and care homes provide twenty-four-hour care for residents. The difference is, in a nursing home there is always registered nurses to provide more specialised care. In this research, I use the term 'nursing home' as this research takes place in a nursing home, rather than a care home. However, I am confident that this thesis will have huge relevance to care homes as well. Bamford (2011) suggests that person's living in nursing homes often have complex care needs and trying to understand and respond to the more intimate and sexual aspects of a resident's personality and relationships can be challenging, both in terms of existing relationships and when relationships develop. There can be no hard and fast rules as each situation and person is unique. With that said, nursing home providers should strive to develop policies which support the rights of all the people who live, visit or work in nursing homes (RCN 2018). A nursing home should be an environment where nurses accept the sexual expression is core to all humans and staff should facilitate individual choices in sexuality expression and intimate relationships. Bauer et al. (2013) and Simpson et al. (2018) claim that most nursing home residents, including persons living with dementia, long for closeness, miss being touched in an intimate way and value various expressions of their sexuality.

Sexual Expression and Person-centredness

Person-centred care (PCC) is a concept that is widely used in both nursing literature and nursing research. There is no one specific definition of person-centred care and in fact it can mean different things to different people in different care settings (Gillespie et al. 2004). One theory of person-centred care is underpinned by an existentialist philosophy of nursing that sees each person as a unique individual with their own beliefs and values (McCormack & Titchen 2017). It is underpinned by values of respect for personhood, an individual right to self-determination, mutual respect and understanding (McCormack and McCance 2017). Person-centeredness is fast becoming core to the main underpinning philosophy and vision for nursing care, certainly in the Western world, including dementia care. However, it is less clear if sexual expression is considered core to this theory. The way in which nurses understand sexual expression seems incomplete and positioned in both

stopping them or at least minimising them. Therefore, to improve the life and overall well-being of people with dementia, person-centred interventions need to be established to respond to rather than manage a wide range of sexual expressions. The only way to get a real insight into the lives of people with dementia is to give them a 'voice': enabling them to speak of their individual needs.

From all my initial thoughts and reading I began to construct possible research questions and aims. The ones I settled on are shown now.

The Research Question, Aims and Objectives

There are two research questions guiding this study. They are:

What is the meaning of sexual expression in persons living with dementia who live in a nursing home setting? And;

How is sexual expression experienced and understood by the nurses providing care?

The aims of this study are:

- To gain knowledge on meaning of sexual expression in persons living with dementia in a nursing home setting.
- To explore how sexual expression in persons living with dementia is understood by nurses working in the nursing home.
- To explore the relationship between sensuousness and sexual expression in person-centred nursing (this aim was added later).

The objectives of this study are:

- To find out from persons with dementia their experiences and views on sexual expression through conversational interviews.
- To explore this sensitive topic in a dignified and respectful way by working with a rigorous consent framework to include adults with incapacity (AWI).

- To observe nurses at work and have conversational interviews with them to find out about their experiences of sexual expression by persons living with dementia.
- To gain insights into the nursing care of persons with dementia in the nursing home, useful for nurses in Scotland and beyond.

Structure of this Thesis

The thesis is presented in a series of chapters that are outlined as follows. This chapter illustrated the background to the study and offers an outline rationale for why I believe sexual expression needs to be explored through a person-centred lens. This chapter also outlines the research question, aims and objectives.

In Chapter Two I will discuss the philosophy underpinning this research. The chapter is divided into two parts. Part one, focuses on the profound philosophical question that is: 'what is a person?' and what my ontological position is on personhood. I describe classical traditions of personhood, before focusing on the work of Maurice Merleau-Ponty and Mark Johnston, which are the philosophers that I have connected with and been inspired by the most. I finish part one with a discussion of how my ontological beliefs connect with my values of sexual expression. This is followed by part two, where I take my philosophical beliefs and construct them into ontological, epistemological and transformational principles that forms the tentative theoretical framework for this research.

Then in Chapter Three I critically review the BPSD model. In healthcare sexual expression by persons with dementia is universally predominantly viewed through the BPSD model. I argue it is important to uncover the origins and review its principles. In this chapter, I propose that BPSD is outdated and does not align with values and principles of person-centredness. I conclude this chapter by arguing that a new framework is needed to view sexual expression in persons living with dementia.

In Chapter Four, I take my philosophical underpinnings from Chapter Two, and my critique of BPSD from Chapter Three, and I propose an original conceptual

framework called, the 'Sensuous Framework'. I introduce and define two related concepts, 'sensuous' and 'sensuousness' that will form the theoretical foundations for a framework I then go onto present. The Sensuous Framework then provides me with a set of coherent and related concepts embedded in person-centredness and my philosophical beliefs, which forms the foundation for this research.

My attention in Chapter Five refocuses on the topic of sexual expression in persons living with dementia. I present a literature review which discusses the importance of sexual expression in persons living with dementia. This review also draws upon evidence which informs us of the cultural perspectives of sexual expression and intimate relationships involving persons living with dementia. Finally, to provide justification for this specific research, I focus on how sexual expression is understood and experienced by nursing working in nursing home environments.

In Chapter Six, the methodology which underpins this study will be explicated. In keeping with my tentative theoretical framework, laid out in Chapter Four, I have created a unique methodology. The methodology for this research focuses on existential phenomenology blended with additional person-centred principles, along with ideas from sensuousness. I conclude this chapter by laying out the key methodological principles for my research.

In Chapter Seven I provide an overview of the methods derived from my methodological principles. I will briefly outline issues arising in the study and described how I accessed the lived experiences and got closer to the phenomenon of sexual expression. This chapter describes the research context, my engagement with the participants and how I immersed myself within the topic and phenomenological writing.

This leads into Chapter Eight, where I present the findings of this study. In this chapter, through my interpretations, you will get a feel of the nursing team's lived experience of caring for persons living with dementia who imbue sexual expression. You will be able to gain insight into the lived experience of sexual expression in persons living with dementia who are living in a nursing home. I provide each

participant the space within this chapter to share their unique story, before engaging with an analytical synthesis to discover the essence of sexual expression in persons living with dementia from the perspective of both the nurses and persons living with dementia. To conclude Chapter Eight, I propose four definitions that describe the phenomena the lived experience of sexual expression in persons living with dementia from the participants.

In Chapter Nine I place the phenomena of sexual expression in a broader context. I describe the concealed meanings that lie within the phenomena of sexual expression. I then focus on how the findings of this research connects with sensuousness by describing a new practical framework called 'The Sensuous-Sexual Expression Framework'. I conclude Chapter Nine by looking forward and offering implications for practice, research and education.

I conclude this thesis with Chapter Ten. In this I discuss the strengths of this study and how I have achieved rigour by ensuring this research was carried out based on person-centred principles. In contrast, I also address the possible limitations of this research. To end this thesis, I discuss my pathway to impact plan, before I bring this research project to an end.

Chapter Two: Philosophical Underpinnings

Introduction

Person-centredness is not just a theory that nurses, and allied healthcare professionals choose to adopt to shape their practice. It is much more than that. From my perspective, person-centredness should come from within and should not be limited to what we *do* in our workplace. Person-centredness is more than how we approach our work and care giving. Person-centredness is a way of being and something I strive to be in every aspect of life. I consider myself not only to be a person-centred nurse, but a person-centred person overall. Through this PhD, I am now exploring my abilities of being a person-centred researcher. As a researcher within a person-centred worldview, it is important for me to immerse myself in the world of philosophy, to unravel and make sense of my values and beliefs in order to understand how I view the world and so I can construct my own research paradigm and ensure it is both appropriate and rigorous. Once I, as the researcher, have a sound understanding of my ontological perspective on personhood, this will lead onto shape my epistemological views, which in turn influences the research methodology.

In this chapter, I aim to present the philosophical underpinnings for this research. I will discuss my philosophical exploration of what it means to be a person and share the beginnings of my theoretical framework that will shape the rest of this research. As I was developing this chapter, I felt it was a long read with a lot of information to get into one chapter. Therefore, I have organised this chapter into two parts. In part one, I explore and critique various traditional positions of personhood. I then discuss the philosophers that I have resonated with and how I have found a philosophical niche with embodiment philosophy. I will conclude part one by discussing how embodiment philosophy connects with my values and beliefs on dementia care and sexual expression. This will then prepare the way for the content in part two, which will draw on my discussion in part one to create and present my theoretical framework.

Part One: Personhood

Even though, in everyday language, the word 'person' is used as the singular term for people, the concept of 'person' has been debated for as long as philosophical thought existed (McCormack and McCance 2017). As this research is situated within a person-centred philosophy and ethos, part of the process is to explore and understand what it means to be a person (Dewing et al. 2017). There are many different philosophical positions on what constitutes a person. Therefore, understanding my personal values and beliefs about what is a person and what constitutes personhood, gives greater clarity on person-centredness and how that shapes nursing practice and research (Dewing et al. 2017). Part one of this chapter will focus on what I regard the main philosophical questions of personhood, and therefore I will discuss my ontological position on 'what is a person' by considering five different philosophers from the 17th century right through to the present day. Therefore, the aim of part one of this chapter is twofold. Firstly, I will explore my philosophical position to advance the concept of embodied personhood in a way that is relevant for my research. Secondly, I will argue that viewing persons living with dementia as embodied beings as a minimum can enhance dementia care practices and research. I will also discuss my beliefs about how persons are sexual beings and how sexual expression is connected to personhood.

Philosophical Traditions of Personhood

Philosophy attempts to make sense of our experience and tries to answer 'big' questions by seeking a comprehensive, internally consistent, rational accounts of the world and our place in it (Torchia 2008). One of the major questions that has puzzled philosophers for centuries is 'what is a person?' and who and/or what deserves the right to personhood. For example, is living as a human being enough to be a person and if so, what qualities and characteristics do human beings have that give us personhood, that non-human animals lack? Or do animals have an equal right to personhood as human-beings? In fact, some philosophical positions put some animals on a hierarchy over some human beings (Singer 1979; Sidgwick 1909). Furthermore, some people and cultures argue that non-animal organisms are

persons. For example, the Whanganui River in New Zealand was granted the same legal rights as a human being, as the local Māori tribe values the river as an ancestor (Warne 2020). Taking this debate even further, in some cases artificial intelligences, such as robots, have been classified as a person. Recently, a robot was granted citizenship in Saudi Arabia which sparked controversy as the robot was of female-appearance and this robot has more rights than human women in Saudi Arabia (Griffin 2017). This specific situation is, therefore, not only an issue around personhood but also an issue around female equality. Looking at these few examples alone it can be clear to see that there are many different views to consider when exploring personhood and understanding one's ontology. This section will look at several philosophers and what I interpret as their stance on being in the world and thus, our personhood. The philosophical ideas which will be core to my research are the ideas of embodiment (Merleau-Ponty 1964) and the significance of our emotions (Johnson 1999). In addition to embodiment and emotions, the ideas that meaning arises to use through a person's senses (Merleau-Ponty 1964) and desires (Schroeder 2015) are key theories that contribute to the philosophical underpinnings of this research. I will now set out my understanding of these ideas and show why separately and together they are included in my paradigm.

Rationality and Self-Awareness

Many philosophers and theorists argue that it is the 'mind' and the ability to be rational, self-aware and reflective is what classifies personhood. In the Cartesian worldview, and predominately in Western thought, the mind and body are separate. For René Descartes (1596-1650) the body is just a chunk of the physical world that happens to be casually contiguous of the soul (Lakoff and Johnson 1999). For Descartes, the mind is disembodied, and it consists of mental substance, while the essence of the body consists of physical substance. He argues that the only essence of human beings is the ability to reason and therefore, imagination and emotions, which are bodily, are excluded from human reason and are not part of the essence of human nature. Descartes claims the essence of human beings has

nothing to do with our bodies. However, I see a major flaw within this position. We need our bodies to be alive. The Cartesian worldview suggests that a mind is separate from the body and it is our 'mind' that gives us all reasoning, meaning and knowledge. However, from my perspective, no Cartesian dualistic person, with a mind separate and independent of the body, exists. Therefore, it also appears to be that Western society incorrectly, uses the words 'brain' and 'mind' interchangeably. The term 'mind' has cognitive overtones and more pragmatic connotations. We have a brain, and it is one key part of the entire pattern of the embodied person, but a Cartesian 'mind' that can live on without a body does not exist.

However, the dualistic Cartesian view is currently still strong among philosophers and current healthcare evidence. For example, Peter Singer, a philosopher and an animal rights activist, believes that some animals are more entitled to personhood than some human beings are as he argues that rationality is a core characteristic of personhood (Singer 1979). Singer proposes to use the term 'person' in the sense of 'a rational and self-conscious being' (1979). A 'non-person human' is a being who is undeniably a member of our species based on biology and genetics, but who is incapable of the conscious activities typical of those members when they are alert: thinking, feeling, hoping, experiencing pleasure and pain (Singer 1979). In Singer's view, animals have more value as persons than a young human baby or a human being with advanced Alzheimer's disease who has reduced cognitive ability. This position resonates strongly with the position of seventeenth century English philosopher John Locke who was interested in the care of personal identity. His suggestion is that the word 'person' stands for:

'...a thinking, intelligent being, that has reason and reflection, and can consider itself, the same thinking thing, in different times and places; which it does only by that consciousness which is inseparable from thinking.'

(Locke 1964, II.xxvii.9)

Locke suggests here that part of what makes a someone a person, is their ability to recognise past experiences as belonging to them. Additionally, this position suggests that babies and older people with declined self-awareness are lesser persons or even not persons. We can see that the Locke's argument advances from the Cartesian body-mind dualism view as a person should have the ability to think, reason and reflect. Locke claims that personhood can be given when there is evidence of someone having the ability to be self-reflective.

Locke's position sits uncomfortably with me as I believe that the ability to be rational and self-aware does not give someone or something full entitlements to personhood. People who have reduced cognitive abilities and a decline in rationality, still gain meaning from their experiences in life. Therefore, I reject the Cartesian, Lockean and Singer's speciesism philosophical positions as each position has the potential to exclude people living with dementia from personhood and devalues their existence in this world.

Autonomy and Morality

For Immanuel Kant (1724-1804), to be a person one is required to understand one's own state of consciousness and experiences and, in having such, one can ascribe similar states of consciousness. Kant also believes that what distinguishes persons from things is the ability to 'act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end' (Paton 1964). He argues that all persons are bound under 'universal moral laws' known as moral imperatives, that we have to obey through 'freedom of the will' (Wood 2018). Kant always places freedom as an absolute priority over all other values in all circumstances including friendship, love, community building, respect for nature, empathy and so on. Kant believes that we should have strong moral grounds to overcome our bodily feelings and needs (Wood 2018). He goes to great lengths to describe the battle that rages between our bodily and rational natures. According to Kant, our bodily needs and wants would reduce us to mere brutes, if they had their way, so that the moral will must develop remarkable strength to overcome this onslaught of bodily temptation

(Lakoff and Johnson 1999). Therefore, self-control, self-reliance, and self-discipline are crucial qualities of morality and thus, Kant's position on personhood.

Additionally, in Kantian philosophy, the body, as the seat of passion and desire, is a source of internal evil and so is a threat to moral action. For example, Kant suggests that whenever we use our bodies non-purposively for sexual pleasure, a violation of autonomy occurs (Wood 2018). Kant asserts that our sexual attributes are given to us for the natural end of procreation and if sex is not directed towards this, then a human being is immoral. He claims that the use of one's sexual attributes is immoral because:

'a man gives up his personality when he uses himself as a means for the gratification of animal drive...he makes himself a loathsome thing, and thus deprives himself of all self-respect'

(Kant 1785, p. 408).

This highlights how much Kantian philosophy devalues the body and the importance of our bodies having emotions and desires. It is evident here that Kant's moral theory has played a major role in the Christian tradition. I agree with Kant's argument regarding that the body the source of emotions and desires. However, where I profoundly disagree with his position saying that it is the source of 'internal evil' and a 'threat to moral action'. Rather, emotions and desire provide us with valuable meaning and brings us closer to understanding who we truly are and what makes each one of us unique. Specifically, with regards to sexual expression, our ability to have sexual desires are part of who we are as persons. Our expression of our sexual thoughts, feelings, desires, fears, hopes, and dreams, we experience through our body, and I do not view the gratification of these emotions and desires as in-moral. Dumpleton (1992), published an interesting book providing a fresh Christian perspective on sex and spirituality. He argues that sexuality is the whole part of our nature, it comes into every part of our physical being and in all our relationships. He claims that the Christian outlook fails to acknowledge the 'miracle' of human sexuality (Dumpleton 1992). Dumpleton's (1992) new-fangled Christian

perspective disregards the belief that bodily pleasure is sinful. Rather he argues that pleasure is an important aspect of sexuality and without its mystery none of us would be living in this world. I concur with Dumpleton's (1992) view in that each of us has a body, and we need physical and emotional stimulation to feel alive, and human sexuality is intrinsically part of this.

Kant is not the only philosopher to suggest that the autonomous decision making, and freedom of the will is crucial to what is a person. Having influences from Kant and Descartes, Frankfurt attempts to differentiate 'persons' from animals or things. Frankfurt (1989) believes that the difference between a 'person' and a 'non-person' is the structure of their will. He argues that having what he calls 'second order desires' distinguishes our will from other animals and thus what gives someone the right to personhood. Desires alone cannot separate 'persons' from animals as both human beings and animals have 'first order desires', for example, 'I want some food'. However, Frankfurt states that persons have second order desires, which means persons can desire to desire things, e.g. 'I wish I wanted to be friendlier' or 'I wish I did not want ice-cream so much'. Frankfurt states that the freedom of will is not just about *having* second-order desires. Freedom of will is when there is an alignment of our second-order desires about our first order desires that ends up motivating our actions (Frankfurt 1989). In other words, it is when the desire we want to motivate our action ends up being the one that motivates our action or when our second order desire 'beats' our first order desires. Frankfurt believes that the freedom of the will is simply the exercise of second-order desires, and then you are autonomous for your own actions.

However, some human beings for example, a young child or someone with advanced cognitive impairments might not be able to draw upon second-order desires. Therefore, the position of Kant and Frankfurt would suggest that babies and persons living with advanced dementia would be classified as a lesser or 'non-person'. However, having the ability to act upon second order desires is not a requirement for personhood. In fact, if someone is not able to have second-order desires, we get to know that someone in greater depth as what we are perceiving

and seeing is not mediated by second order desires and they are arguably displaying their authentic self. For example, if someone who lives well with dementia and (s)he who does not have second order desires, is having a bad day and is feeling really upset they might display this emotion through crying or shouting because that is what they are truly feeling and thinking. On the other hand, if I am feeling upset, I might feel like crying. However, I have no doubt that if I was in any form of company or had any daily task to do, my second order desire to hide the fact that I am upset would 'beat' my first order desire to cry. Thus, I would be concealing my authentic self in that moment in time.

So, according to Kant and Frankfurt, I would meet the criteria of being a person because my second-order desires 'won' against my first order desires. Whereas the person living with dementia would not be, due to a possible decline of rationality and decision-making skills. However, the questions I ask are: who is being true to themselves in this situation; and who is being more authentic? The person living with dementia is being truer to themselves by expressing their emotions, compared to me who is trying to hide, through my second-order desires and my rational thought, my feelings of being upset. Therefore, I argue that the ability to have rational thoughts, and thus freedom of will, does not meet the criteria for determining who or what deserves personhood.

To summarise so far, I have discussed briefly, although sufficiently for this thesis, how five different philosophers, from the 17th century through to the present day, present their perspectives of personhood. Even though they all have slightly different standpoints on what is a person, they all appear to believe that the 'mind' and the body are separate entities, and it is the 'mind' that gives our personhood. The philosophers place immense value on someone's cognitive ability, their capability to rationalise and self-reflect, and their capacity to make autonomous decisions. However, I see major flaws with each of these positions as many people, such as persons living with dementia, would not meet the criteria for personhood if they are viewed in this way because their critical thinking skills and rationality may have declined over time. Up to this point, none of the philosophers that I have discussed

place any significance on the body as a way of being in this world and a source of personhood, human experience and knowledge. The philosophers that I have discussed up to this point have dismissed something fundamental about personhood and that is the notion of embodiment.

Embodiment

The English Oxford dictionary defines 'embodiment' as 'a tangible or visible form of an idea, quality, or feeling'. However, for some philosophers, and for me personally, the term 'embodiment' has a much greater meaning than this. According to French philosopher Merleau-Ponty (1962), it is precisely through our body that we have access to the world. In other words, embodiment is our *being* in the world. Our bodies and the relationship between our bodies and the world is crucial for our being and our ability to gain meaning and knowledge; something that the previous philosophers have ignored. Therefore, I have resonated most with Merleau-Ponty and his ontological approach of embodiment. His most important contribution to philosophy is his phenomenology account of perception and embodiment, which he argues are not mere properties of minds of subjects, but constitutive elements of our being in the world or in other words of our bodies (Merleau-Ponty 1962).

Merleau-Ponty describes perception as, not an event or a state in the mind, but an organism's entire bodily relation to its environment (Merleau-Ponty 1962).

According to Merleau-Ponty (1962) perception is essentially finite and perspectival: 'my body is my point of view on the world' (p.410). The structure of perception, we might say, is the structure of the body. It is not our 'mind' that allows us to make sense of the world; it is our body that is our expression of the world (Carman 2008).

In contrast to the philosophical traditions of Descartes and Kant, Merleau-Ponty believes that all forms of human experience are through our intimate relationship between the body and world and that is where personhood lies. Human experience and personhood are grounded in and shaped by our bodily orientation of the world (Carman 2008). Thus, even though a new-born baby is not self-aware and has not developed reasoning and rationality, the baby gains meaning and perceives through their body and of being in the world. For example, new-born babies search for light

and need human skin-to-skin contact. Likewise, with persons living with advanced dementia, they might not have rationality or second-order desires, but their bodies are still gaining meaning of the world. They are still seeing, hearing, touching, learning, and still can 'feel' and express emotions. All person's experience emotions, sensations and desires, which all originate from our embodiment, regardless of cognitive ability.

Even though reflection and conscious thought helps up to form and understand our own identity, I argue that Locke and Singer miss a crucial aspect of what it is to be a person, the notion of body-subject. Not only does our existence as a person emerge from our embodiment, but also our existence as to be understood as expression of our individuality at all levels, including body language, habits, our characteristic mannerism and gestures and so on (Matthews 2006). That we have such an immediate and intuitive bodily sense of ourselves is what Merleau-Ponty wants to recover and explore in his phenomenology. He argues that we have body memory which is the totality of implicit dispositions of perception and behaviour mediated by the body and laid down during earlier experiences. For example, we are proprioceptive aware of being warm or cold, of the positions and movements of our limbs, of whether which parts of our bodies are being touched – all without observing ourselves from judgements based on observation (Carman 2008). In other words, our body provides us with great wisdom, and we gain essential knowledge and meaning, without rationality and judgment.

Merleau-Ponty reminds us that there is a certain amount of non-consciousness in the consciousness of anything, even of essences. In *'The Phenomenology of Perception'* (1962), he describes the body as the field of our possibilities, as being found among things, but also as the origin of our distance from things, and as participating in creating this distance. Perception discloses a world and Merleau-Ponty wanted to bring philosophical and psychological back to the naïve understanding of perception not merely having something 'in your head', but as being orientated in a surrounding world. His central philosophical idea is that perception is a bodily phenomenon, not a mental event occurring at the end of a

chain of physical causes and effects. It is the body that perceives, not this 'mind' as discussed in Cartesian philosophy. By having such an immediate and intuitive bodily sense of others, the world and ourselves, we need to recognise that it is our body that perceives and allows us to make sense of the world.

Merleau-Ponty also believes that the body and the world are not two distinct things, sinews of a common flesh, threads and reaction, but like a single woven texture (Carman 2008). We are woven corporally both into the material world we perceive and onto the social world we inhabit. We do not stand outside the world, peering in at it, but already inhabit and incorporate it from within. Merleau-Ponty states:

'One's own body is in the world just as the heart in the organism'.

(1962 p. 209).

Therefore, having a decline in rationality does not cease our being and someone's personhood, as they are still embodied within the world and have a constant relation with the world. Our experiences with our relation between body and word influence our beliefs, values, social being, culture, personality, sexuality and relationships (Melancon 2014). Thus, I argue that we are in a constant relationship with the world and are forever learning and gaining meaning through our interactions.

So far in this chapter, I have rejected the philosophical traditions of the mind-body dualism of personhood. I have voiced my disagreement on various theories that having the ability to be rational and self-reflective are core attributes to being a person. It was concerning that so many philosophers disregarded the body and its significance to what constitutes a person. Therefore, I have introduced Merleau-Ponty's idea of 'embodiment' as a way of being in the world. I will now move on to discuss how emotions, senses and desires are primary concepts of embodiment and perception.

Emotions, Senses and Desires: Gaining Meaning Through the Body

Traditionally in Western culture, reason is seen as independent of perception and bodily movement (Lakeoff and Johnson 1999). However, Johnson's work aims to show how the body generates meaning even before self-consciousness has fully developed. He turns to cognitive neuroscience to further explore bodily origins of meaning including images, qualities, and metaphors. Meaning is rooted in the body's physical encounters with the world and argues that all these aspects of meaning-making are deeply aesthetic. Johnson pays close attention to the importance of emotions in generating meaning through the body. He argues that emotions are not just feelings of our present body state, although they are at least that (Johnson 1999). The body state itself is always a measure of how things are going for the organism in its setting, and so emotions arise and are directed out into the world. In this way, Johnson (1999) argues that emotions are a primary means for our being in touch with the world and are a crucial part of gaining meaning and knowledge of different situations.

Referring to the work of John Dewey, Johnson (1999) argues that emotions are processes of organisms' environment interactions as they involve perceptions and assessments of situations in the continual process of transforming those situations. The body is always connected with emotions and, even though critical thinking and skills may be absent or have declined. Emotions and bodily feeling are states of both responses to and remaking of experience (Johnson 1999). We say, 'I am fearful' but this really means 'the situation is fearful', and it is our bodies that feel and express this sense of fearfulness (Johnson 1999). Therefore, it is our bodies that tell us we are in a situation that is fearful. There would not experience an emotion without the body and flesh, but neither would there be an emotion if there were not a situation. Thus, Johnson reiterates Merleau-Ponty's idea that emotions are created through the intertwining of the body and the world as one. Dewey (1925/1981) claims that if emotions are merely private, interior, subjective responses, then they tell us nothing objective about the world. However, once we see that emotions exist precisely because of the ways they are connected to our shared world and permit

us to function within it, then it becomes possible to recognise their crucial role in our communal well-being. Therefore, emotions are a fundamental part of human meaning and they are integral to our ability to grasp the meaning of a situation, the meaning of others and the meaning of ourselves (Johnson 1999).

The long-standing prejudice in Western philosophy against cognitive meaning to emotional experience that is due primarily to the widespread belief that emotions are not conceptual (Johnson 1999). However, Johnson argues once we stop thinking of concepts as abstract, disembodied entities and see them rather as bodily processes, we can recognise that the crucial role of emotions in the meaning of situations, persons, objects, and the complexities of emotional life is not sufficient reason for denying that emotions give us meaning. The body carries forward meaning of a situation. As Gendlin (1997) states our bodies implies what we want to do and say to carry our situations forward. Through our embodied understanding, we learn how to go on with our thinking, and how to carry a situation forward in a fulfilling way.

Johnson (1999) also calls on the work of Portuguese-American neuroscientist, Antonio Damasio, who brought new attention to the role of emotions and feelings in consciousness, judgement, and reasoning. Damasio (1999) claims that feeling an emotion is our principle way of being aware of changes in our body state, as our bodies respond to changes in their situation (both their internal and external situation). He argues that emotions are key components of complex bodily perception, assessment, internal monitoring, self-transformation, motivation, and action (Damasio 1999). Another way of putting this central point is that by the time we feel an emotion, a mostly unconscious assessment has occurred of the situation we find ourselves in, and in cases where we are functioning optimally, we have frequently already taken steps to transform the situation in order to enrich the quality of our experience. We have perceived and understood our situation in a certain light, although with very little or no conscious reflection (Damasio 1999). Therefore, Damasio (1999) argues that emotions play a role in transformation and

suggest that persons are in a constant mode of becoming for as long as they are alive.

Johnson (1999) states that we must recognise that it is our body that thinks, and that our thoughts and feelings do not simply emerge from our quest for truth, but from the situations in which we are placed. Thinking is not a skill that the 'mind' can do, it is an embodied action, and so 'acts of thought' also constitute situations that must have pervasive qualities (Malecon 2014). Even our best scientific thinking stems from the grasp of qualities and bodily emotions. It arises from the feeling that a situation is problematic or that it calls out for interpretation or an explanation (Johnson 1999). Johnson challenges many objectivists by asking 'if thinking, conceptualising, imagining and reasoning, is not an activity of embodiment, then where does it come from?' According to the objectivist view, sensations are perceptual givens that arise when the outside world impinges on our sense organs, whereas concepts are supplied by the mind to allow us to recognise what is given in sensation (Johnson 1999). What this objectivist view of cognition gets right is that concepts do indeed help us to understand, or make sense of, our sensory experience. However, what is wrong about this view is the way it treats concepts either as discrete mental entities or abstract entities as something different from sensations, perceptions and feelings.

There are two other concepts I want to discuss alongside the importance of emotions as I feel they are equally central to human perception and embodiment, and for this research. The concepts are 'senses' and 'desires'. I am going to begin with the significance of our senses and our ability to experience sensations. Our senses are person's ability to see, hear, smell, taste and touch. Our sensations are our lived experience of our senses. For Merleau-Ponty, sensations are the 'unit of experience' and are the most:

'rudimentary of perceptions, and, as a modality of existence, it is no more separable than any other perception from a background which is in fact the world.'

(1962, p. 241).

Merleau-Ponty claims that the lived body is directed towards an experiencing world and when we perceive an object or a phenomena, our sensory inputs (sensations) synthesise together as an experience of that object or that phenomena. Therefore, sensations and emotions are a way of experiencing the world that we are intertwined with and filled with meaning. The sensing organs associated with each sense send information to the brain to help us understand and perceive the world around us. This is the faculty of perceiving by a means of sensing through the sense organs (e.g. touch, sight, smell, hearing, tasting) and experiencing emotions. The sense experiences are situated on the level of pre-reflexive embodied lived experiences of a communion that precede objectivation and representation (Merleau-Ponty, 1962). Sensations are an intrinsically part of being-in-the-world; the body and the embodiment of senses are always already culturally mediated (Kuepers 2013).

I suggest that, along with emotions and senses, desires lie core at our being-in-the-world. Desire is familiar to everyone who has ever wanted to drink water, desired to know what has happened to an old friend, longed for intimate touch or craved a more fulfilling and financially rewarding job. However, its familiarity does not make it easy to give a theory of desire (Schroeder 2006). In Western culture, both past and present, desires are usually understood as something abnormal, avaricious, and excessive. In other words, much of the time, desires are something that is often viewed as something that needs to be controlled and suppressed in humans. I have drawn up on the pleasure-based theory of desires that Schroeder (2006) and Strawson (1993) discuss, compared to the action-based theory of desire which often fails to acknowledge the significance of pleasure in human desire. According to these philosophers, a person moved by a desire always enjoys what is desired. Schroeder (2006) argues that:

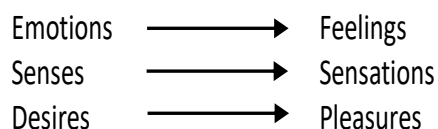
'For an organism to desire p is for the organism to be disposed to take pleasure in it seeming that p and displeasure in it seeming that not-p.'

(2015, p. 6)

Thus, we become aware of our desires through experiencing pleasure, or indeed, displeasure. From my perspective, pleasure is our conscious awareness of our desires. Strawson (1993) defends a pleasure-based theory on two grounds. First, Strawson (1993) holds that having a desire for anything requires consciousness, and pleasure and displeasure are the states of consciousness most closely linked to desire. Secondly, Strawson (1993) holds that it is conceivable that there be persons who would lack dispositions to act through rationality, but who would have dispositions to feelings of pleasure and displeasure, and that these persons would seem to have desires for the things that would please them. This may include persons living with neurological injuries who live through their capacities to feel and experience pleasure (Strawson 1994). It is generally accepted that desires come on a continuum of strengths in that we can have light desires with some things and stronger desires with others. The desire to experience pleasure is innate (Pollock 2006). Taking all this into account, desires are embodied and essential to human experience.

Overall, I suggest that emotions, senses and desires lie at the heart of embodied perception. Emotions, senses and desires are core to our personhood and contribute to our being-in-the-world. Our emotions, senses and desires become alive to us through our feelings, sensations and pleasures respectively. In other words, it is through our feelings, sensations and pleasures, persons become aware of their emotions, senses and desires. *Figure 3* illustrates the relationships between emotions and feelings, senses and sensations and desires and pleasures.

Figure 3: Experiencing our Emotions, Senses and Desires Through Feelings, Sensations and Pleasures.



In summary, there is an obvious and prominent fact about human beings that Merleau-Ponty and Johnson capture well: we are our bodies. The human body is central to our everyday life and is fundamental to personhood. By taking principles from both Merleau-Ponty's position of embodiment and Johnson's work on gaining meaning through the body, it can be said that rationality, autonomy, and self-awareness are not crucial requirements of being a person. I have also discussed the significance of emotions, senses and desires in relation to embodiment and personhood. A person is an embodied being, who experiences the world through their emotions, senses and desires. Now that I have explored my own philosophical understanding about what it means to be a person, I am going to move on to how the concept of embodiment can influence dementia care and from this, the connections between my philosophical position and sexual expression.

Embodiment in Dementia Care

Even though, in the last decade there has been a notable increase in enhancing person-centred practice within dementia care, according to Kontos and Martin (2013), many dementia care practices are still premised on models of dementia that denies the body as an agent in the constitution and manifestation of personhood. Instead there has been a focus on mind and self (Kontos and Martin 2013). A statement from Cohen and Eisdorfer (1986, p. 22) stating that *'the victim of Alzheimer's disease must eventually come to terms with...the complete loss of self'* still seems to be a strongly embedded in dementia care. This view, central to biomedicine, seems to stem from the traditional philosophy of the Cartesian and Lockean assumptions that the mind and body are separate, and it is the mind and the cognitive ability to be self-reflective that establishes personhood. Therefore, it is unsurprising that persons living with dementia have been viewed as 'losing self' if traditionally, we have adopted the position that rationality and having a 'mind' is what constitutes personhood. Until we challenge this view that the 'mind' holds the key to our personhood, we can never fully achieve person-centredness in dementia care as the person living with dementia will most probably, subject to the progression of the dementia, to be positioned as a 'non-person'.

Tom Kitwood is a major influence in the field of dementia care in the UK and he is the first academic who applied the concept of personhood to people living with dementia (Kitwood 1997). He believes it is being in relation with others that is the primary consideration for being a person. According to Kitwood, personhood is defined as:

'a position or social relationship that is bestowed on one human being by 'others' in the context of relationship and social being'.

(Kitwood 1997, p. 8).

Kitwood claims that the core attributes of persons as having agency, sociability and sentience (Kitwood 1993). What is fundamental about Kitwood's work is his rejection of the philosophical assumptions of the mind-body dualism, in which the person living with dementia would be viewed as 'mindless' and thus not a person. Kitwood reinstates the significance of the ability to feel, to perceive and experience the world subjectively in bestowing personhood upon someone. Kitwood's work and definition is a huge breakthrough for person-centred dementia care, but for me personally, it has got its weaknesses. Kitwood places a huge amount of emphasis on being in relation with others as fundamental to being a person and that personhood is bestowed on by others. Being in relation with others is vital for wellbeing and human flourishing, however, there is something more fundamental before the ability to be in relationships: to be embodied. For me, Kitwood has not overtly considered the idea of emotionality and discuss the notion of embodiment. In order to be in a relationship with self or others, and be a social being, one needs to be an embodied human being in this world who experiences emotions, sensations and desires.

If I reject the Cartesian and Lockean views on personhood and identity I cannot say that a person ceases to exist with their decline in rationality or the lack of ability to be self-reflective. They are embodied in this world and therefore, is fully entitled to be seen and treated as a person. Additionally, due to the traditional dualistic view

of the mind and the body, when persons living with dementia have been expressing themselves with their bodies it can often be seen as meaningfulness and somewhat troublesome. Therefore, Merleau-Ponty and Johnson's work is crucial in valuing the significance of the body in relation to personhood. By adopting the philosophical stance of Merleau-Ponty's embodiment, persons living with dementia are viewed as active beings in the world and gain meaning through their bodies. Through their bodily being in the world they are interacting with others and with their environment. They are learning and perceiving the world through their bodies and through experiencing emotions, sensations and desires. Thus, persons living with dementia, no matter what cognitive ability they have, have a lot of knowledge to share about the world that they perceive and how they express themselves through their body. In fact, when persons living with dementia express themselves through their body, they are expressing their authentic being in that moment of time.

Embodiment and Sexual Expression

As my PhD is looking at persons living with dementia and perceived sexual expression, it is important for me to always re-focus my thinking and consider how my philosophical underpinnings shape my research topic and my researching of it. Therefore, I am going to now discuss how sexual expression is viewed through an embodiment philosophy which I elected to adopt for this research, based on the philosophy of Merleau-Ponty and through which I established connections between my values and his work on the 'sexual being'.

In his *Phenomenology of Perception* (1962), Merleau-Ponty wrote a chapter entitled 'The Body in its Sexual Being'. What Merleau-Ponty (1962) argues is that sexuality is neither transcended in human life nor shown up at its centre by unconscious representations. He claims it is at all times present there like an atmosphere. Like the intentionality of consciousness, the body is always attracted to something or others outside of its own body. Therefore, there is an ever-present interfusion between sexual desire and existence. Merleau-Ponty invites us to try and see how a thing or a being begins to exist for us through desire and/or love and that we shall

thereby come to understand better how things and beings can exist in general (1962, p.154). We embrace and experience our sexual presence and intentionality through our body, our sincere emotions, senses and desires; and this does not end until our bodies cease to exist. Sex and intimacy include our emotions, senses and desires about how we perceive and experience love, intimacy, touch, pleasure and passion. Our relationships with our bodily being and others shape our sexual presence along with society and culture. Desire, pleasure, joy, love are not mental entities (Johnson 1999); it is through our bodies in which we express ourselves and respond our sexual and intimate needs. Our sexual being comes from our deepest roots of emotion and our interactions with our worlds.

Western culture and society places huge emphasise on our ability to be rational beings, but like Lakoff and Johnson (1999), I suggest that we need to place more emphasis on the body and our ability to experience emotions, desires, and senses and the importance of gratifying those emotions, desires and senses. Rather than seeing our bodily desires as meaningless and 'the source of evil', we need to celebrate our body as it is through our ability to experience emotions, desires and senses that we are in touch with who we are as individuals and our world. The way sexual expression needs to be viewed is from the perspective that our body and its capacity to experience emotions, senses and desires is at the core of our very being. Therefore, our sexual desires and feelings contribute to who we are as persons. The body is a sexual body, and it is part of our existence. While I am adopting several ideas from Merleau-Ponty supported by more recent ideas from Johnson, I also accept that multiple ideas intersect around how older persons as sexual bodies are portrayed and represented in western culture.

To reiterate, there continues to be ageist myths about how older people are asexual, and sexual expression is not for the aged (Syme et al. 2017). In addition to this, sexual expression has been placed under the umbrella term of behavioural and psychological symptoms of dementia (BPSD), which suggests that due to cognitive decline, persons living with dementia having sexual desires is unnatural and consequently, should be 'managed' or stopped through primarily pharmaceutical

interventions. It appears that the BPSD model views sexual expression as a meaningless bodily action. The BPSD model seems to be influenced by Cartesian values in that, the person with dementia is no longer 'themselves' as their cognitive ability has decreased and thus, their body is just a physical 'thing' responding behaviouristically.

Given my position is that all persons are sexual beings, and sexual needs and desires are an embodied experience, I dismiss the point of view that sexual expression should be 'stopped' or 'minimised' by persons living with dementia. Rationality and the ability to self-reflect are unnecessary attributes for sexual expression and to feel emotions of love, companionship, intimacy and sexual desires. These emotions originate from our bodily relations with ourselves and others. My argument is if we view sexual expression through the philosophical perspective of embodiment, we can understand how our body is central to experiencing meaningful emotions. We can begin to understand that persons living with dementia must use their bodies to communicate with the world, and to express their desires with others. Sexual expression, or indeed any other form of bodily expression, should not be viewed as a problematic behaviour that is caused by disinhibition. Referring back to my opinion on Frankfurt's theory on second-order desires and Kant's theory on morality and making autonomous decisions, any embodied expression by persons living with dementia as 'how they truly feel that moment in time'. Therefore, the person living with dementia is expressing their authentic being in that moment and that should be viewed as an opportunity to provide holistic, person-centred care as the persons is expressing authentic emotions, desires and needs. By applying these ontological principles of embodiment to this research, individuals living with dementia will be viewed as persons who are fully experiencing and gaining meaning from the world they live in. Sexual expression will not be viewed as challenging and meaningless.

Summary of Part One

The worldview of personhood I resonate most deeply with is the embodiment perspective described by Merleau-Ponty and Johnson who explored how meaning is

gained through the body. Our being and all our experience, knowledge and meaning comes from our bodily-being in the world, or in other words, through embodiment. From the overview of different Western philosophical theories dating back to the 17th century it is clear that the ability to be rational and to be a 'thinker' has dominated the philosophical puzzle of personhood. My argument is that the body is foundational to the coherence of embodied personhood. Merleau-Ponty's phenomenology is not a theory of mental representation, but a descriptive account of perception as a mode of being in the world. Also, the work by Johnson emphasises that it is the body, not the mind, which not only feels and expresses emotions but is our source of thinking. By synthesising the philosophical ideas of Merleau-Ponty and Johnson I show how embodiment is crucial to our being of the world and how we gain meaning. By combining the work of Merleau-Ponty and Johnson it can be understood that the body is an agential role in the constitution of personhood and the fundamental source of knowledge. In the next section I take forward these values and beliefs on personhood and discuss how this has shaped a theoretical framework for this research. Using the principles of personhood as being, knowing/doing and becoming, I discuss my ontological, epistemological and transformational principles that form a framework for this research.

Part Two: Being, Knowing and Becoming

Background Reflections

A theoretical framework is one of the core foundations of my research and has shaped the rest of my study and this thesis. Thus, establishing a theoretical framework that is true to my values and is robust enough to extend knowledge in the topic further is crucial for this research. Part one of this chapter explored various philosophers and different positions and viewpoints, and I emphasised that I felt an immediate resonance and connection with Maurice Merleau-Ponty and his notion of embodiment. Further, I discovered Mark Johnson's work, who very fittingly as a follower of Merleau-Ponty, puts forward an argument that places a central importance of our bodies and emotions, and how they are fundamental in everything we experience. In addition to emotions, I have also discussed how senses and desires are part of our embodiment and are significant in how we create meaning in the world which we experience.

As I progressed my studies, I became aware that I had been viewing my ontological and epistemological principles separately. However, I knew I needed to ensure that both my ontological principles and my epistemological principles should intricately relate with each other. Ultimately, my ontology and epistemology will influence my methodology, and accordingly I will have created my personal research paradigm for my PhD. All aspects of the theoretical framework should seamlessly fit with one another and flow in a way that each aspect should influence and compliment another (Dewing et al. 2017). When I take a step back and look at my ontology, epistemology and research topic separately, I felt pleased and content with my position and my principles. What challenged me, however, is trying to fit all my ideas and principles together to create a framework that would be central to my research. They all connected in some way, but I struggled making the clear links and lacked inspiration to create something unique and meaningful to show my philosophical and theoretical thinking.

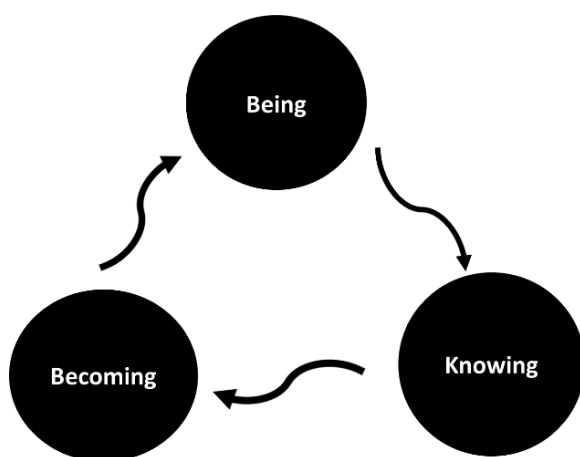
I needed to find a way to comprehensively demonstrate how my worldview and ideas can be a strong foundation for my research. I spoke with my supervisory team about it and they advised me to keep immersing myself within the literature and keep 'playing around' with my ideas. I was reassured that something will happen that will make it all start to click and come together. A couple months and supervisions later, I still felt that I was getting nowhere. I was continuing to explore Merleau-Ponty's and Johnson's ideas and even though I was gaining a deeper understanding of their work I did not get anywhere to creating a framework.

From undergoing the exploration of self and my own values, and connecting them with a philosophical position, I 'knew' I had a worldview which would carry me through this research. I had this 'gut feeling' that my philosophical thinking, described in part one of this chapter, would provide me with my ontological and epistemological principles for this research. However, having a gut feeling was a good starting point, but I needed this embodied knowing to be unconcealed and to be more tangible. According to Lawrence (2012), we can access our intuition and embodied knowledge through dreams, symbols, artwork, dance, yoga, meditation, contemplation, and immersion in nature. For me, my embodied knowledge came alive to me through my dreams and in moments of contemplation. As someone who has vivid dreams on a nightly basis, it is not uncommon that my thoughts and at times, a vision, can galvanise during my sleep. I would often keep a pen and a piece of paper on my bedside cabinet to try and capture these moments as soon as I awakened. Moments of contemplation were also important for me to capture my embodied knowing. This was time where I literally just stood or sat contemplating. I did not need to read, write or draw, just listen to my embodied knowledge and let something come to me. Van Manen (2002) would argue that it was not my thoughts that were elsewhere, but I was elsewhere. It was during these moments of either night-time dreaming or 'day-dreaming' which I felt I had experienced crucial breakthroughs when constructing a theoretical framework for my research.

I was introduced to the being-knowing-becoming cycle (*see figure 4*) at the nursing strategy launch of the institution I am registered with (Queen Margaret University

(QMU), Division of Nursing Strategy 2019-2022). Through moments of contemplation and having a dream, I started to link it to my philosophical beliefs. I started to work through these concepts and their relationships to see if it would help me consolidate my feelings and ideas. I kept 'zooming in and out' of the model to look at each section individually, and then collectively as a whole. I felt that in order to understand it as a whole, I needed to strip back the model and look at one section or one concept at a time. I am now going to discuss each section of my adaptation of the cycle individually, before concluding with the chapter by illustrating my ontological, epistemological and transformational principles.

Figure 4: The Being-Knowing-Becoming Cycle (Adapted from the QMU, Nursing Division Strategy 2019-2022)



Being

I am starting with the concept of 'being'. The 'being' part of this model is my ontology. This is the part I probably feel most confident and grounded with because, as I discovered my philosophical niche and thoroughly described in part one of this chapter. Through my philosophical and personal exploration, I have pinpointed three key ontological principles that are vital for my research. The three key principles are:

- The body is fundamental in our existence and is a subject – not an object.
- Persons are embodied beings within the world.

- Our perception, emotions, senses and desires are crucial to human existence.

It is important to state that there is no order of importance for these three key principles and they are dynamic. The idea that the principles are intertwining together is essential for me. Even though they are each vital principles, it is not until those three principles come together and interconnect with one another, I am content with my ontology. Individually they are important and interesting; collectively they are, in my perspective, what constitutes personhood.

Knowing

I am now going to discuss how my ontology influences my epistemological beliefs and how I believe we 'know' something. It is through our ontological practices that we are able to engage in knowledge creation using the epistemological assumptions of our worldview (Titchen et al. 2017). New knowledge is, as argued by Titchen et al. (2017), always developed by paying attention to relational connectedness with participants and researchers. It is also crucial to blend different ways of knowing and creating supportive research environments and cultures (Titchen et al. 2017). Looking at my ways of knowing I am now content about my view that the body and bodily emotions, senses and desires are crucial in the process of gaining knowledge; knowing is an embodied phenomenon.

Our bodies and bodily emotions, senses and desires are necessary for knowledge and how we make meaning of our world. A deeper understanding of our embodied experience can provide an alternative view of knowledge and knowing. Johnson (1999) puts forward an argument affirming that before there is abstract thinking, before there is reasoning and speech, there is emotion, and it is emotions that lie at the heart of our capacity to experience meaning. Emotions are key components of complex process of assessment, evaluation and transformation and are bodily (Johnson 1999). Feelings are our conscious awareness of an emotion. In other words, feelings allow us to 'know' we are experiencing. Therefore, they are integral to our ability to grasp the meaning of a situation and to act appropriately in

response to it. In the same way, feelings are our embodied knowledge of emotions, sensations are our embodied knowledge of our senses, and experiencing pleasure are our embodied knowing of our desires. Persons become aware of their emotions, senses and desires through their feelings, sensations and pleasures, respectively.

Additionally, there is no single truth and a person's lived experience, and perceptions are vital for knowing. Reality is subjective and linked to human perception and what persons know in and through their bodies and practices is primary point of access. According to Lakoff and Johnson (1999), ways of knowing have no mental representation. It is through our bodies and being-in-the-world we have 'lived experience' in which we gain knowledge. Human experience is the main epistemological basis for phenomenology (van Manen 2014). Thus, knowing and doing are connected. Plus, the intentionality of the body means it reaches out to connect with the world and 'does'. The concept 'lived experience', used by Merleau-Ponty, possess special epistemological and methodological significance as the notion of lived experience announces the intent to explore *directly* the prereflective dimensions of human experience (van Manen 2016). It is through human experience we can come to 'know' things, gain meaning and understanding. According to van Manen:

'lived experience names the ordinary and the extraordinary, the quotidian and the exotic, the routine and the surprising, the dull and the ecstatic moments and aspects of experience as we live through them in our human existence.'

(2014, p. 39)

For Merleau-Ponty, 'the world is not what I think, but what I live through' (1962, p. xvi). Merleau-Ponty's (1962) view is that it is only through experiencing the world that we can begin to develop knowledge of it, and only then that we can begin to think of an objective world independent of our

experience. Understanding develops through reflection and interpretation of the experience. Because we cannot separate ourselves from who we are, all interpretations are in a particular context, setting, and moment – our ‘being-in-the-world’. Knowledge of the world is gained through one’s existential experience of it, through a myriad of structures of experience including sensations (hearing, tasting, seeing, feeling, and smelling), memory, imagination, emotion, perception, desire, embodied action, linguistic activity, and social behaviour (Merleau-Ponty 1968). The body is an important epistemological tool for acquiring knowledge of the world (Lundgren-Gothlin 1996).

My key epistemological principles are:

- Knowledge is gained through our bodies and our interactions with the world and others in the world.
- Emotions, senses and desires are fundamental to gaining meaning through our feelings, sensations and pleasures respectively.
- There is no single truth, and a person’s life experiences and perceptions are highlight valued.

Again, there is no order of importance and these principles as not just concepts on their own but connecting with one another to create ways of knowing. While an existential phenomenology offers an epistemology that incorporates the perspective of the researcher and aims to explore a mode of engagement with the world not previously explored in the context of this research and practice, it does not offer a whole understanding as it does not go beyond language to facilitate expression of pre-reflective knowledge.

Becoming

Now, I am going to focus on the concept of ‘becoming’ and what it means for me in the context of this research. When I think of ‘becoming’, immediately I imagine a person undergoing some form of change or development, enabled by the process of

reflecting on one's values and beliefs and their lived experience. Becoming is about human transformation and flourishing. Persons are never static and there is always an element of transformation throughout existence. To develop these ideas further, I engaged with Heron's (1992) work on Feeling and Personhood, and Mezirow's (1991) theory of Transformative Learning. Even though there are some ideas of Heron that I disagree with (e.g. he takes the position that a person is a fundamental spiritual reality and being a person is an 'achievement'), there are some ideas that I agree with and relate to in terms of my perception on the notion of 'becoming'. What I do agree with, is his idea that learning, intention and action all originate and stem from emotion and feeling. However, Heron was arguing this without explicitly talking about how emotions originate from body and are embodied. Heron (1992) argues that the importance of emotionality in learning is fundamental, which correlate with the position that emotions are essential for making meaning. According to Heron, there are four 'modes' or processes to learning: emotion, imagery, discrimination and action.¹

This emphasises the absolute essential role that emotions play in meaning making and thus gaining knowledge to then inform an action. As previously stated, our bodily emotions are our ways of gaining meaning and thus, are essential for any form of action or change. I then sought out the work of Jack Mezirow and his Transformational Learning Theory. Mezirow discusses the core elements that are crucial for transformational learning. These core elements are: individual experience, critical reflection, dialogue, holistic orientation, awareness of context and authentic relationships. Mezirow (1991) argues that to transform, instead of analyse-think-change, one must see-feel-change. Again, this emphasises the importance of the body and emotions in human transformation. I started to think

¹**Emotion** – the intense, localised affect that arises from the fulfilment or the frustration of individual needs and interests such as joy, love, surprise, anger, grief, fear etc.

Imagery – the ability to generate an individual viewpoint, a unique outlook on life through the use of imagery, e.g. in sense perception, memory, anticipation, dreams, visions, imagination.

Discrimination – the ability to categorise things in terms of classes, to distinguish between one particular and another in perception, to identify similarities and differences. This is also closely tied to Heron's meaning of 'reflection'.

Action – Behaviour/response performed by the person based on the previous three modes.

how this fit into my perspective and beliefs about 'becoming'. I agree that individual experience is fundamental to knowing and reflecting critically on the lived experience is important for transformation. The holistic orientation strongly emphasises the importance of emotions that link to my philosophical position. These core elements feel more comfortable with me and are more of an idea as to what I believe transformation looks and feels like.

I am going to rephrase 'human transformation' to 'authentic transformation'. The importance of learning and transforming in ways that remain true to one's personality, values and beliefs. Transformation and learning might occur, but in ways that contradict or conflict with the person's values. This could happen for several reasons. For example, the person might not be fully aware of their beliefs and have not explored their values, pressures from others or societal expectations and 'norms'. It is not until one critically reflects on their lived experience and understands their values and how it affects them as a person that 'authentic transformation' can occur. Being authentic requires persons to consider factors such as, the meaning of individual relationships, emotional engagement, knowledge and decision-making capacity in determining our 'being-in-the-world' (Heidegger 1927/2010, p. 345). This can be a challenging and vulnerable process. Mezirow (1991) calls it 'leading learners to the edge' and claims transformation is often when people come up against their limitations, go beyond the habitual, experience the unaccustomed, meet, split or break down, face dilemmas, feel insecure, or must make incalculable decisions. This time of vulnerability is challenging and uncertain, yet it encourages emotional intensity and innovation, and in this way, it also promotes authentic transformation.

In his *Phenomenology of Perception*, Merleau-Ponty establishes, against intellectualism, the fundamental and inextricable ambiguity of our lived and embodied experience, our being-in-the-world (Landes 2013). Existentialists are therefore interested in the nature of active, participatory existence (Jones 2003), where we experience the world through our senses, and act on what we perceive (Matthews, 2006). A 'lived body' is always in a state of becoming, rather than being

in a fixed state. Experiential knowing is knowing an entity – person, place, thing, process etc. – through face-to-face meetings and interaction, and it cannot be fully reduced to a set of descriptive statements (Heron, 1981). This approach reoriented philosophy and established the need to adopt an existential analysis and an expressive philosophy that might begin to understand this ambiguous body that is always ‘transforming’ (Merleau-Ponty 1962, p. 205). Becoming is not merely the means to some significant and definite ends; it is a continual process that signifies activity, involvement, change, and potential, ceasing only with life itself. Being a human is a process of becoming; there is no essential self to search for, no knowledge to be discovered that would reveal to one who/what one is. My transformational principles are:

- Persons are in a constant mode of becoming.
- Learning, intention and authentic transformation originate from our emotions, senses and desires as they provide us with feelings, sensations and pleasures respectively.

To summarise, after looking at each section individually, I ‘zoomed out’ to look at it as a whole and to see my ontological, epistemological and transformational principles together. *Table 1*, summaries the cyclical a dynamic principle which shape my research paradigm. However, these principles should be viewed as cyclical and dynamic, rather than fixed and linear.

Table 1: My Being, Knowing and Becoming Principles

Being (Ontology)	Knowing (Epistemology)	Becoming (Transformation)
<p>The body is fundamental in our existence and is a subject – not an object.</p> <p>Persons are embodied beings within the world.</p> <p>Our perception, emotions, senses and desires are crucial to our human existence.</p>	<p>Knowledge is gained through our bodies and our interactions with the world and others in the world</p> <p>Emotions, senses and desires are fundamental to gaining meaning through our feelings, sensations and pleasures respectively</p> <p>There is no single truth, and a person’s life experiences and perceptions are highly valued.</p>	<p>Persons are in a constant mode of becoming.</p> <p>Learning, intention and authentic transformation originate from our emotions, senses and desires as they provide us with feelings, sensations and pleasures, respectively.</p>

Conclusion

In part two, I have taken being-knowing-becoming and applied it to my values and beliefs, and my philosophical underpinnings. This model will be the lens which I conduct my research and explore my topic. As much as they are uniquely crucial individually, they are all connected with each. I do not view them as separate, but as three fundamental notions that come alive when they are all interconnected with other another. They are all in relation to one another, and all influence each other. Now I had an idea on what I was hoping to achieve using my ideas and the concepts of being, knowing and becoming. I discussed how I brought in my philosophical position and values into the model and how I see it as a cycle; three important concepts that all interconnect with each other.

Chapter Three: The Discrepancy Between Behavioural and Psychological Symptoms of Dementia and Person-centredness

Introduction

Since the late 20th century, the 'behaviours' of persons living with dementia have been of increasing interest to many healthcare professionals and researchers in the dementia care field. Unfortunately, the 'behaviours' of people with dementia has been dominated and viewed through the lens of the behavioural and psychological symptoms of dementia (BPSD) model. Over the past two decades there has been a growing worldwide acceptance of BPSD; with its influence seen in many healthcare guidelines, ranging from national UK strategies (The National Institute for Health and Care Excellence (NICE) 2018; Alzheimer's Society 2018) to global health policies (World Health Organisation (WHO) 2017). Currently, there is a considerable emphasis within the dementia care field, placed on the promotion of person-centred care. Person-centred care is now the underlying philosophy in most western healthcare policies for dementia care (Fazio et al. 2018). A core principle of person-centred philosophy is seeing an individual as a unique and complete person, and not just as medical diagnosis such as dementia. The movement towards person-centredness within dementia care has undoubtedly transformed the way people with dementia are viewed, treated and respected within healthcare. However, the way 'behaviours' such as agitation, apathy, wander walking, aggression and sexual expressions are viewed, still seems to be stuck within the biomedical lens of BPSD which, in my opinion, noticeably views the person as having a dementia diagnosis before being seen as a unique individual with values, beliefs, emotions, a life-history, likes and dislikes. There is a clear need for a re-evaluation of BPSD and the time has come to offer a new perspective on 'behaviours' of people living with dementia that proceeds from a person-centred philosophy. Additionally, BPSD is the main theoretical backdrop in which sexual expression is viewed upon, which gives me further reason to critically review the model.

In this chapter I aim to review the creation and the development of BPSD and how it has influenced healthcare practices and has impacted on the lives of persons living with dementia. I will attempt to review the evidence base behind the creation of BPSD, however, I will discuss in the methods section how this has proven to be a challenge. I will address how BPSD is currently 'managed' by reviewing the common tools that are used within healthcare practice to assess behaviours that are seen as 'challenging'. Even though that there is increasing evidence and a movement towards non-pharmacological interventions being used to 'manage' expressions in persons living with dementia, I discuss how non-pharmacological interventions only papers over the cracks of the BPSD model and does not fully align itself to person-centredness. This chapter will show that the biomedical view of BPSD fails to acknowledge that persons with dementia are active beings who are constantly perceiving and creating meaning of their world. I will put forward an argument to show that personal expressions are a normal part of being a person and that their expressions should be much-admired, as they can give us a true sense of what the person with dementia is perceiving, rather than viewed as 'inappropriate' and 'challenging'. This review challenged me to reconsider how I view expressions from people living with dementia and the need for better person-centred responses. I needed to do this work, to ensure I was able to move away from scientific assumptions about dementia and people with dementia to enable space for me to try to get closer to experience as it is lived by people with dementia. To conclude this chapter, I will illustrate and share my own personal thinking and reflections on some key questions that I have been pondering over throughout reading the literature on BPSD and writing this review.

What is BPSD?

BPSD is a model or a theoretical explanation that implies that 'behaviours' such as agitation, aggression, low mood, apathy, wander walking, sleep disturbance, delusions, verbal aggression and sexual expression occur as a 'symptom' in persons living with dementia as a result of their dementia diagnosis. The BPSD model is used by healthcare professionals, researchers and policy makers worldwide (WHO, 2018;

Hersch and Falzgraf 2007) to assess and 'manage' people living with dementia who present with 'challenging behaviours' as research claims that BPSD one of the main explanations for long-term care admissions and is intensely associated with family/caregiver(s) burden (Finkel 2000a). The term 'BPSD' is ingrained within medical and healthcare literature and has been widely accepted by Alzheimer's organisations, government legislations, healthcare policies and care professionals, without undergoing any sort of review or scrutiny. The BPSD model does not make any accommodation for 'behaviours' as natural reactions and responses that stem from our perception of the world and our bodily emotions. Thus, the BPSD model views what is natural human feelings, emotions and expressions as abnormal and problematic, with a view to minimising or preventing such expressions as far as possible. For the purpose of this chapter I am going to refer to what is commonly known as 'BPSD' as 'personal expressions' as they are not a 'symptom' that occurs as a result of having a dementia diagnosis, which will be explained in more depth as this chapter progresses.

As a result of the BPSD model, both pharmacological and non-pharmacological interventions have been recommended and used to 'manage' and 'treat' personal expressions from persons living with dementia (Bjerre et al. 2018; Scales 2017; Robinson et al. 2006). Nevertheless, even though non-pharmacological interventions are the recommended first port of call, it evident that medications such as antipsychotics are still being prescribed regularly in dementia care, even in care that claims to be 'person-centred' (White et al. 2017). Person-centred dementia care is widely accepted as a value-based commitment to supporting people living with dementia and is a guiding principle in care services. Many experts and policy guides claim that responding 'BPSD' using psychosocial interventions is 'person-centred' as they can be tailored to the individual's needs (Scales et al. 2018). However, if we value the perspective that the body and emotions are fundamental for personhood (see Chapter Two), and thus persons living with dementia are viewed as actively being-in-the-world and their personal expressions are meaningful, then there becomes a clear discrepancy between the biomedical

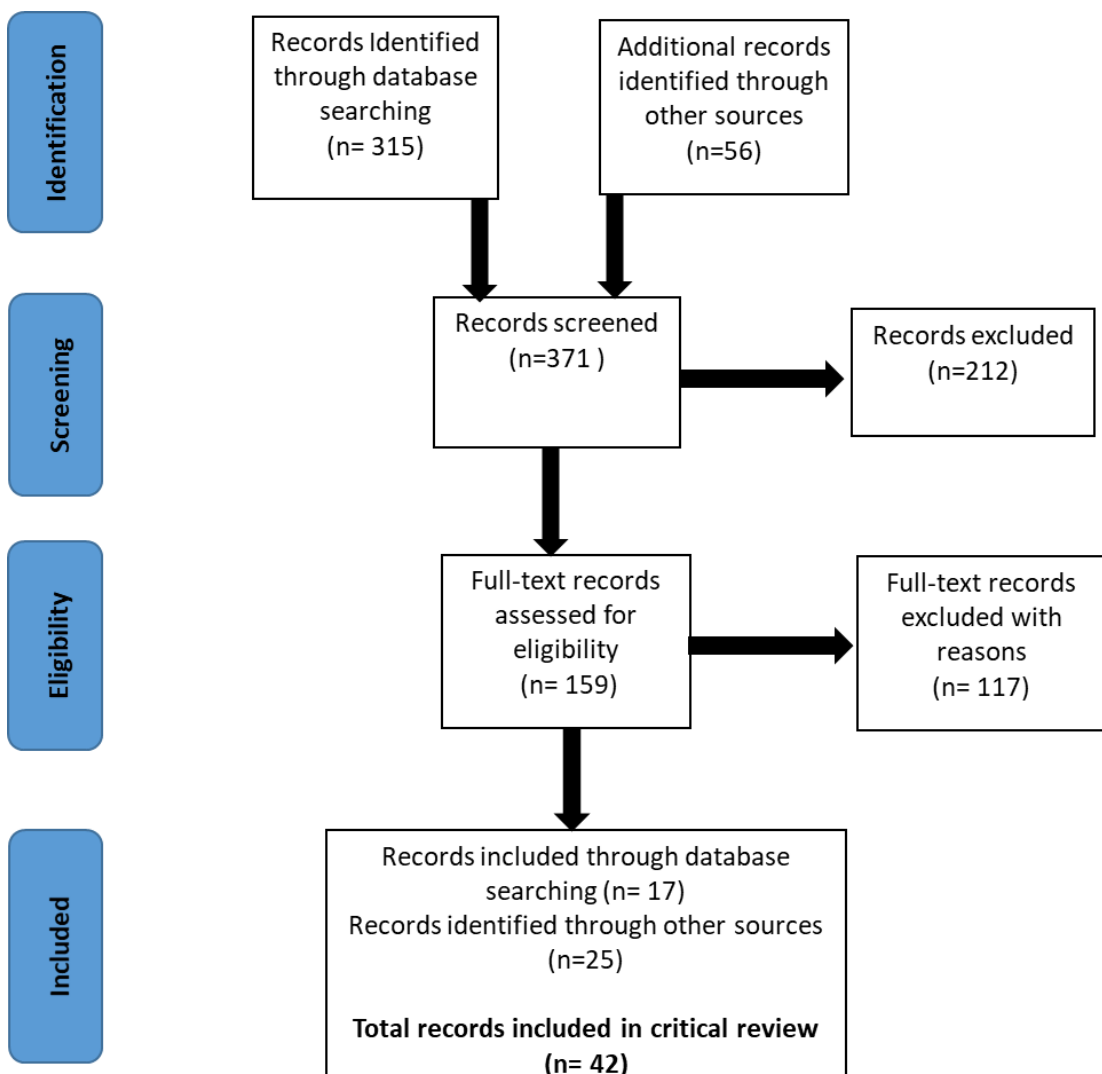
model of BPSD and person-centred care. Therefore, there is an exigent need to re-evaluate the BPSD model and current healthcare practices in regard to personal expressions by persons living with dementia, and to offer a new, refreshing outlook when responding to personal expressions. In order to fully achieve person-centred care, we need to reconsider how we view persons living with dementia and value how they express themselves and their emotions. Then we can respond to these expressions and care for persons with dementia in ways that are sensitive and person-centred.

Method

This review followed a critical review method as it provides a means to identify and critique relevant publications and materials from diverse sources (Grant & Booth 2009). A few of the publications and resources used in this review, especially on the origins of BPSD, are not to be found through the traditional route of database searching. Additionally, a critical review provides a method that encourages a deep analysis and synthesis of the material in order to offer a different perspective and to arrive at new insights (Grant & Booth 2009), which correlates with the intentions of the review. I used the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta- Analyses) guidance (Moher et al. 2009), which aims to help authors improve the reporting of systematic reviews, meta-analyses and critical reviews. Since some of the literature and resources in this review are not research articles, searches for literature begun with, but was not limited to academic databases to find relevant research papers on the assessment and management on BPSD. The databases that were used to locate some of the articles included in this review were CINAHL, PsychINFO, Medline, SCOPUS and Science Direct. The key terms used for the database searches were 'Behavioural and Psychological Symptoms of Dementia', 'Behaviour Disturbances', 'Development of BPSD', 'Challenging Behaviours' and 'Problematic Behaviours' in combination with 'Dementia', 'Persons living with Dementia' and 'Dementia care'. When using the word 'behaviour' in a search term, the UK and the American spelling were both used so that articles with either spelling could be located. A total of seventeen original research articles that

explored the assessment, management or healthcare professional’s experience of BPSD were found through searching the online databases. Other literature evidence was collated through hand-searches of journals, reference lists and searches through Google Scholar. This resulted in gaining a further twenty-five publications which was included in the review (*see figure 5*). From these publications three themes emerged: (1) the origins and developments of BPSD; (2) assessment and assessment tools; and (3) responding to personal expressions in persons with dementia.

Figure 5: PRISMA for BPSD Critical Review



I began the search in 1996 as this was the year when the term BPSD was first introduced at an International Psychogeriatrics Association (IPA) consensus conference in Lansdowne, U.S.A. As one of the aims of this paper is to review how BPSD was created and where it came from, it was important to locate as much information that came from this consensus conference. By searching the IPA's online journal, I was able to locate the conference outputs, a 'Consensus Statement' (Finkel et al. 1996), an 'Introduction' paper (Finkel 1996) and eight discussion papers highlighting the IPA's new focus on BPSD. In the introduction paper, Finkel (1996) informed the reader that all the participants of the conference received:

'approximately 60 background articles, so that speakers could focus on the specific issues of determining exactly what the behavioral disturbances of dementia are...'

(1996, p.215)

For this review I intended to trace the 'background articles' that were used to inform the discussions at this conference to discover the evidence-base and information behind the creation of BPSD. However, this has proven to be a serious challenge. From searching the online databases mentioned above, I was not able to locate any reference list or information regarding the sixty background articles. The information regarding the BPSD consensus conference in 1996 was published in *International Psychogeriatrics*, a journal produced by the IPA. The journal produced a special supplement within volume three, which was dedicated to the BPSD conference and was not made available online to the public in 2005. I collated and read each paper in the supplement, and hand-searched each reference list in the articles within the supplement, yet no more was mentioned on the background articles that informed the conference and the creation of BPSD. I then attempted to get more information through supplementary searching in Google Scholar, but this similarly generated no further findings.

Having no luck with locating the desired articles I contacted the IPA directly to see if they could offer any assistance in providing any more information on the

'background articles'. However, despite contacting a number of individuals, no one could provide me with any insights to what articles were used for the conference or a list of who attended. They did provide their latest specialist guide on BPSD (IPA 2015). Interestingly, this was adapted from an educational pack originally published in 1998, in the aftermath of the BPSD consensus conference. As much as the guide provided some useful references and evidence, I was still no further forward in finding out more about the conference and the background evidence. After searching through various avenues without success, I contacted numerous professionals who wrote information published on the BPSD consensus conference and/or the specialist pack, to see if they could offer any information. I then made contact personally with the lead author of the *Introduction* and the *Consensus Statement* along with other members of IPA who wrote about BPSD. No one could provide us with any information on the 'background articles' or any further information on the consensus conference. Instead, I was directed back to the IPA, who said they did not have any relevant information about the 'background articles'. I have set out my attempts clearly to assist readers of this paper and others who may wish to undertake a similar search and to assist in the degree to which I can challenge the establishment of BPSD and its value. The background evidence was fundamental to shaping the way the experts at the consensus event went about its deliberations and without having the knowledge of this information I have no idea about the nature, rigor or quality of the evidence.

Findings: The Origins and Development of BPSD

Prior to the term BPSD being introduced in 1996 at an IPA consensus conference, I found that the term 'behavioural disturbances' was already in use, including by the IPA, to describe some 'behaviours' seen in persons living with dementia. The IPA was founded in 1982 by a small group of psycho-geriatricians and became a multidisciplinary organisation with the vision of improving the mental health of the elderly around the world (Sadavoy 2007). While their language sounds outdated now, prior to the twenty-first century, dementia was first classified as a normal part of ageing (senility) and then as a mental health condition and was consequently

considered as belonging to the field of psychiatry (Berrios 2017), and so the description was of its time. There has since been a shift in focus away from the traditional biomedical model in dementia care that focuses on the disease in favour of embracing a more social disability model (Hacking 2010; Wolff 2010). However, the way behaviours are positioned still seems to be trapped within a biomedical-pathological lens and seems to have made slower progress in modernising itself. Consequently, there are still many negative portrayals and consequences for persons with dementia and those associated with them.

The IPA convened their consensus conference for two main purposes. According to Finkel (1996) this was to first, review the current knowledge on behavioural disturbances of dementia and second, to reach a consensus in four critical areas: (i) definition of the symptoms, (ii) causes of the symptoms, (iii) description of clinical symptoms, and (iv) agree research directions. This implies that behavioural disturbances were both relevant and a priority. Sixty experts from sixteen countries participated in the original conference to produce a consensus statement, and to review and discuss issues related to aetiology, nosology and nomenclature, criterion validity, clinical signs and symptoms, caregiver input and issues, cross-cultural and transitional considerations and future research directions (Finkel 1996). It is unclear who the sixty experts were who contributed to the consensus conference, as there is no definitive published list. At that time, experts would be most likely be regarded as senior healthcare professionals; most likely in medicine or clinical research in the specific field or area of interest. Since the development of BPSD, the landscape of who is an expert (Bryden 2019) and how to develop a consensus statement has changed significantly.

According to Roukis (2015) a consensus statement is the end product developed by an independent panel of subject matter experts. The panel members should be made up of multidisciplinary professionals and ideally should include persons who are living with the disease/condition under consideration. This emphasises the position that persons living with dementia should be involved in any key decisions and developments as no one knows more about living with a dementia diagnosis

more than someone living with dementia. Hearing the voices of persons living with dementia is now essential within research, policy development and changes within healthcare practices so that they can reflect the needs and wishes of the targeted population (Dementia Alliance International 2015). It would have been highly unusual for persons with dementia to have been involved in the consensus conference or in any related decision making, given the standard views held about dementia and persons with dementia at that time both within medicine and across society more broadly. The IPA has continued with its position and in 1998 an educational pack for healthcare professionals on the importance of identifying and treating BPSD was published with updated versions published in 2002, 2010, 2012 and 2015. The IPA claim that:

'BPSD are an integral part of the disease process and present severe problems to patients, their families and caregivers, and society at large... BPSD are treatable and generally respond better to therapy than other symptoms or syndromes of dementia'.

(IPA 2015, p.1.6)

This highlights at a number of levels, how persons with dementia express themselves and that many of the resulting behaviours remain fundamentally problematic for professionals. However, the IPA more recently claims 'behaviours are treatable and respond to therapy'; although they do not specify if this is pharmacological or non-pharmacological. The BPSD perspective is based on behavioural science, which has its roots in positivism and in an outlook that supports mind-body dualistic assumptions; whereby the ability to be rational and to draw upon second order desires is key for human beings and for personhood and regards emotions as evanescent and meaningless.

Participants from the BPSD consensus conference agreed that research needed to focus on the:

'Development of a well-defined reference to different types of behavioural and psychological signs and symptoms and their response to pharmacologic and non-pharmacologic interventions'

(Finkel et al. 1996 p, 499).

The IPA claim that non-pharmacological interventions should be the first port of call in responding to BPSD (Finkel et al. 1996). However, what is interesting, and contradictory is that even though the IPA emphasise that non-pharmaceutical therapies should be the initial choice for the management of BPSD, the consensus conferences and the educational packs for BPSD were supported by an unrestricted grant from a major international pharmaceutical company. Although acceptable at the time, it still raises several ethical questions. Further, other evidence from a wide range of literature at that time also indicates that pharmaceutical management was a first line response in different care settings (Banerjee 2009; Lawlor 2002; McShane 2000).

An update conference was held by the IPA in 1999, on the research directions of BPSD, three years after the original consensus conference. The group consensus was that the umbrella term BPSD continued to serve a useful purpose for dementia care, and that BPSD should continue to be used to refer to the wide range of symptoms that occur with dementia. During the three years between the BPSD conferences there was a rapid increase in pharmacological research on BPSD supported by government agencies and by pharmaceutical companies (Finkel 2000a). Within this time period, at least a dozen major studies had taken place looking at the effects of various drugs on their use of managing BPSD such as risperidone (De Deyn et al. 1999; Katz et al. 1999), carbamazepine (Tariot et al. 1998), and haloperidol (Devanand et al. 1998). The interesting point here is that all the clinical studies on the use of psychotropic medications, in this time period, were sponsored by either the National Institute of Mental Health (NIMH) or an international pharmaceutical company (Finkel 2000b). According to Finkel (2000b), some of the companies hired geriatric psychiatrists with expertise on BPSD, and the

IPA sent a panel to one pharmaceutical company to help in the design of successful research protocols. Even though the results from the 1999 conference on BPSD state that any form of BPSD should be treated non-pharmacologically wherever possible, it is not surprising that the evidence available for practitioners was positioned within BPSD and advocated using pharmacological interventions for persons living with dementia. It would be another decade before the position of using pharmacological treatment as a first line response was significantly questioned and for policy (Banerjee 2009) and research to reflect alternatives. The IPA declare that funding for studies that compare pharmacologic and non-pharmacologic interventions, either separately or in combination, is difficult to obtain. The usual explanation given is that non-pharmacologic approaches lack a theoretical basis and frameworks. Indeed, Finkel (2000b) argues that the field has 'not yet been able to get beyond this limitation'. This may in fact be a representation of what theoretical knowledge has been positioned as valuable and what has not.

Currently, there continues to be significant amounts of dementia research that directly or indirectly draws on BPSD. Direct reference can be seen in the titles, abstracts and keywords as well as core content, such as background, methodology, and use of assessment or measurement instruments/tools and presentation of results, discussion and recommendations. There is also a growing body of research that may position research more loosely within BPSD by offering a critique of it or by drawing on person-centred ideas, but nevertheless offers a paradox. As when investigated, it is evident that it continues to draw on core ideas and instruments or tools that have a BPSD foundation. Scales et al. (2018) argues that non-pharmacological approaches to address BPSD are person-centred. Even though non-pharmacological approaches are an improvement from psychotropic and other sedative medication prescriptions, I argue that this does not go far enough. In my view, many non-pharmacological interventions are still advocating use of BPSD as these interventions originate from the behavioural perspective that underpins

BPSD. They are still based on the assumptions that feelings and displays of emotions are unnatural and pathological, in that they occur directly as a result of a dementia.

BPSD Assessments Tools

In the late 1980s up to the mid-1990s there had been a dramatic increase in interest in 'behavioural issues' associated with dementia and there was a sudden spurt in the developments of scales to measure 'behavioural issues'. Examples of some scales developed at that time are can be found in *table 2*. It is important to note that in the descriptions of the assessment tools in *table 2*, I have used the language and terminology that the authors themselves have used to describe their assessment tool. In this section I am going to review the assessment tools associated with 'behavioural issues' for persons living with dementia and I will argue there is a need for a much more sensitive, person-centred assessment approach when assessing emotional expressions. All these various assessment tools are very similar in that they focus on evaluating the 'behaviours' of persons with dementia, including the type, severity and frequency of the behaviours. According to the English Oxford Dictionary *behaviour* is defined as 'the way in which one acts or conducts itself, especially towards others'.

Table 2: BPSD Assessment Tools

Tool Name	Author (Date)	Purpose	What does the tool assess/measure?	Who was the tool created for?	How is the tool used?	Reliability and/or Validity Tested (YES/NO)
Behavioral and Emotional Activities Manifested in Dementia (BEAM-D)	Sinha et al. (1992)	The BEAM-D Scale was developed for the operational assessment of troublesome and disruptive behaviours in dementia.	The BEAM-D scale is a tool, split into two sections which assesses targeted behaviours (e.g. aggression etc.) and inferred states (e.g. depression etc.) respectively.	Caregivers, healthcare professionals and researchers.	The BEAM-D is split into two categories: targeted behaviours and inferred states. The targeted behaviours section assesses hostility/aggression, destruction of property, disruption of others' activities, uncooperativeness, noncompliance, attention-seeking behaviour, sexually inappropriate behaviour, wandering and hoarding behaviour. The inferred states assess depression, delusions, hallucinations, anxiety, and appropriateness/stability of affect, appetite changes and sleep patterns. Each item has its own score point rating scale and the time frame to use for this tool is one week.	YES

The Behavioural Pathological Rating Scale for Alzheimer's disease (BEHAVE-AD).	Reisberg et al. (1987)	To specifically measure the occurrence and severity of behavioural problems in people with Alzheimer's disease.	The BEHAVE-AD measures behavioural disturbances in seven major categories (paranoid and delusional ideation, hallucinations, activity disturbances, aggressiveness, diurnal rhythm disturbances, affective disturbances and, anxiety and phobias).	Caregivers and/or healthcare professionals of persons living with Alzheimer disease.	The BEHAVE-AD is a 25-item scale that measures each symptom is scored on a 4-point scale of severity where 0 = not present, 1 = present, 2 =present, generally with an emotional component, 3 = present, generally with an emotional and physical component. The tool also contains a 4-point global assessment of the overall magnitude of the behavioural symptoms in terms of disturbance to the caregiver and/or dangerousness to the patient.	YES
The Behavioral Syndromes Scale for Dementia (BSSD)	Devanand et al. (1992)	The BSSD provides detailed examination of symptoms of behavioural disturbance.	The BSSD focuses on five syndromes: disinhibition, catastrophic reaction, apathy-indifference, sun-downing, and denial.	Family members or caregivers of someone living with dementia.	Each item of the BSSD is scored with a 3 point scale, on the basis on both frequency and severity (0= No info; 1= Absent; 2= Minimal; 3= Mild; 4=Moderate; 5= Severe; 6= Extreme). The scale is used over a 1-week period.	YES
Blessed Dementia Scale (BDS)	Blessed et al. (1968)	BDS was developed to assess an elderly person's ability to perform activities of daily living	The BDS is a mental and Behavioral rating scale (with subscales) used to assess the progress and severity of dementia. The scale registers changes in managing daily activities such as deterioration of	Healthcare professionals and family members	The BDS is split into three main sections: changes in performance of everyday activities; changes in habits; changes in personality, interests, drive. Each item in the changes in performance and the changes in personality is given one point if the item applies to the person being	YES

			faculties (misplacing, forgetting), loss of cognition for people, and loss of bodily and toilet functions.		assessed. For the changes in habits it is scored on the four-point scale (0-3) depending on how severe the changing in habit is.	
The Brief Psychiatric Rating Scale (BPRS)	Overall and Gorham (1962)	The BPRS was originally developed to characterise psychopathology and to measure change in psychopharmacology research.	The SCAG scale is a 18 item tool which assesses a person's somatic concern; anxiety; emotional withdrawal; conceptual disorganisation; guilt feelings; tension; mannerism & posturing; grandiosity; depressive mood; hostility; suspiciousness; hallucinatory behaviour; motor retardation; uncooperativeness; unusual thought content; blunted affect; excitement and disorientation.	Researchers in psycho-pharmacological research and healthcare professionals/ caregivers.	Each of the 18 items is measured against an 8-point severity scale (0-7). 0= not assessed; 1= not present; 2 = very mild; 3= mild; 4= moderate; 5 = moderately severe; 6= severe; 7 = extremely severe.	YES
The Cohen-Mansfield Agitation Inventory (CMAI)	Cohen-Mansfield et al. (1989)	To assess the frequency of manifestations of agitated behaviours in elderly persons in nursing homes. Later	Measures agitated behaviours that is always socially inappropriate, and can be manifested in three ways: (1) it may be abusive or aggressive towards self	The tool was originally developed for researchers, but has commonly been used by	The CMAI may be self-administered by a caregiver or it may be completed by interviewing a member of staff or family caregiver. The CMAI is a rating questionnaire consisting of 29 agitated behaviours,	YES

		versions of the CMAI were developed for community use and a disruptiveness scale was added to each behaviour.	or other; (2) it may be appropriate behaviour performed with inappropriate frequency, such as constantly asking questions and (3) it may be inappropriate according to social standards for the specific situation, as in taking off clothes in the activity room. Disruptiveness is how disturbing the behaviour is to staff, other residents, or family members.	healthcare professionals, family caregivers, social workers, activity directors who care for older persons.	each rated on a 7-point scale of frequency over a two week period, ranging from never showing an agitated behaviour (1 point) to several times an hour (7 points). Later versions of the CMAI added a 5-point disruptiveness scale as well as frequency scale of each agitated behaviour, which ranged from Not at all disruptive (1 point) to extremely disruptive (5 points).	
The Columbia University Scale for Psychopathy in Alzheimer's Disease (CUSPAD)	Devanand (1997)	The CUSPAD was developed to assess the symptoms of psychosis, behavioural disturbances, and depression in people with Alzheimer's disease.	The CUSPAD Scale focuses on four key areas of psychopathology in Alzheimer's disease over a one month period. The scale assesses if someone with Alzheimer's disease has any delusions, hallucinations, behavioural disturbances (e.g. wandering, agitation, physical aggression, violent outburst) and depression.	The tool was designed so it can be administered by a clinician or trained interviewer to the relatives or caregivers of someone with probable Alzheimer's disease.	Each of the four main sections of the CUSPAD tool (delusions, hallucinations, behavioural disturbances and depression) has its own set of questions associated with the symptom. The majority of the questions require a yes/no answer and is given a score (0=no; 1=yes). The time frame for each question is one month.	YES

<p>The Consortium to Establish a Registry in Alzheimer’s Disease (CERAD) Behavior Rating Scale</p>	<p>Tariot (1996)</p>	<p>The CERAD Behavior Rating Scale was developed to provide a standardised method of evaluating the frequency (but not severity) of a wide range of pathological behaviours and psychiatric symptoms seen in patients with varying degrees of dementia. The scale should not be used if the persons with dementia is known to have a previous mental health history or those of have delirium.</p>	<p>The CERAD Behavior Rating Scale is a 46 item assessment tool to measure a variety of psychopathologic signs and symptoms, including changes in mood, apathy, anxiety, agitation, aggressive behaviors and psychotic features (hallucinations and delusions). The scale also includes the assessment of pathologic behaviours less commonly associated with psychiatric disorders such as wandering or repetitive questioning.</p>	<p>Researchers, family members, healthcare professionals and any other caregivers. The tool was designed to be used by an informant (e.g. family member or nurse) and not by the subject (person with dementia).</p>	<p>Each of the 46 items is scored based on the frequency of the behaviour. A score of 0, 1,2,3,4 8 or 9 can be given for each item. A score of 0 is given if the behaviour or symptom has not occurred since the illness began. 1 = the behaviour or symptom has occurred for 1-2 days in the past month; 2 = the behaviour or symptom has occurred for 3-8 days in the past month; 3 = the behaviour or symptom has occurred for 1-2 days in the past month; 4 = the behaviour or symptom has occurred for 16 days or more in the past month; 8 = the behaviour or symptom has occurred but not in the last month; 9 = Unable to rate. Additionally, the interviewer has the option to rate how valid the informants appeared to be given a 3-point scale (0-2). 0 = interview appeared valid; 1 = interview is probably acceptable; 2 =information from interview is of doubtful validity.</p>	<p>YES</p>
<p>The Neuropsychiatric Inventory</p>	<p>Cummings et al. (1994)</p>	<p>The Neuropsychiatric Inventory (NPI), or NPI -Questionnaire</p>	<p>The NPI originally examined 10 sub-domains of behavioural functioning:</p>	<p>To be used by researchers and caregivers in any</p>	<p>Each of the 12 behaviours initiate with a “Yes” (present) or “No” (absent) question. If the respondent</p>	<p>YES</p>

		(NPI-Q) was developed to assess dementia-related behavioural symptoms which they felt other measures did not sufficiently address.	delusions, hallucinations, agitation/aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, and aberrant motor activity. Two more sub-domains have been added since its development: night-time behavioural disturbances and appetite and eating abnormalities.	healthcare or community setting and does not require cooperation from the person living with dementia.	answers “No” the caregiver moves onto the next question. If the caregiver reports “Yes” (s)he rates the severity of the symptoms present within the last month on a 3-point scale and the associated impact of them and/or others (i.e. Caregiver distress) using a 5-point scale	
The Philadelphia Geriatric Center Affect Rating Scale	Lawton et al. (1996)	The Philadelphia Geriatric Center Affect Rating Scale was designed for the use of research and other staff in assessing positive affect and negative affect in residents living with and without dementia	The 6-item Philadelphia Geriatric Center Affect Rating Scale was designed for the use of research and other staff in assessing positive affect (pleasure, interest, contentment) and negative affect (sadness, worry/anxiety, and anger).	Researchers and healthcare professionals working with people living in residential settings.	Older people living with or without dementia are to be assessed to have a positive affect (pleasure, interest, contentment), or having a negative affect (sadness, worry/anxiety, anger) by direct observation of facial expression, body movement, and other cues that do not depend on self-report.	YES
The Quality of Interactions Schedule (QUIS)	Dean et al. (1993)	The Quality of Interactions Schedule (QUIS) is an observational	The QUIS is a method of systematically observing and recording interactions without becoming involved	Researchers and healthcare professionals in the acute care	The quality of the interaction is rated by using three categories: (1) positive social; (2) basic care/neutral; and (3) negative. Positive social interactions	YES

		strategy in which social interactions between residents and care staff are coded as positive social, positive care, neutral, negative protective or negative restrictive.	(non-participant observation). It measures older people – care staff interactions, and visitor/family members – care staff interactions.	setting working with older people.	are interaction that show warmth, are respectful and enabling. Basic care or neutral interactions neither undermine nor enhance people. Negative interactions lack warmth and/or respect.	
Sandoz Clinical Assessment – Geriatric (SCAG) Scale	Shader et al. (1974)	The SCAG scale was developed to assess psychopathology in the elderly. It was created as a tool for geriatric psychopharmacologic research	The SCAG scale is a 19 item tool which assesses a person’s mood/depression; confusion; mental alertness; motivation; irritability; hostility; bothersome; indifference to surroundings; unsociability; uncooperativeness; emotional lability; fatigue; self-care; appetite; anxiety; impairment on recent memory; disorientation; and overall impression of patient.	Researchers in psycho-pharmacological research.	Each item on the SCAG tool is measured on a 7-point scale where a score of 1= not present and a score of 7 = severe.	YES

The language and behaviours included within the assessment tools gives insight into the values and positioning of researchers and the research at the time they were constructed. The assessment tools were designed to be used for caregivers such as healthcare professionals and in some cases, family members to assess and evaluate the ‘inappropriate and/or challenging behaviours’ of people living with dementia. However, what is ‘inappropriate’ and/or ‘challenging’ can be highly subjective and therefore, the assessment tools run the risk of being inaccurate as the result depends on what the instrument user is regarding as ‘behavioural issues’ and what they regard as ‘inappropriate’. Additionally, some scales and tools measure caregiver distress as a means of evaluating the behaviour(s) of the person with dementia. One of the most prominent assessment tools used for persons living with dementia is the Cohen-Mansfield Agitation Inventory (CMAI), a tool which was originally developed to assess agitation among individuals with dementia living in nursing homes (Cohen-Mansfield et al. 1989). This tool was then adapted for people living with dementia who live in the community (Cohen-Mansfield 1991). It is an observational tool which has been used often by healthcare professionals and researchers to measure agitation levels for persons living with dementia (Brett et al. 2017). Agitation is defined by Cohen-Mansfield and Billig (1986) as,

‘inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the agitated individual.’

(p.713)

Agitation can include a wide range of actions such as pacing, wandering, general restlessness, screaming, hitting etc. These actions are measured on frequency using a seven-point scale ranging from ‘never’ to a ‘few times an hour’, and they are measured on frequency over the preceding two weeks, through the observation of someone living with dementia by a staff member or caregiver. Other labels have been used for these expressions such as ‘problem behaviours’, ‘disruptive behaviours’, ‘challenging behaviours’ and ‘inappropriate behaviours’ and more

recently, 'behaviours of distress' and 'behaviours of unmet needs'. However, Cohen-Mansfield (1996) stated that the term 'agitation' was chosen because of its use among staff members in long-term care settings and because it is a precursor to more extreme behaviours. This tool consists of 29 'agitated behaviours', each rated on a seven-point scale of frequency over a two-week period, ranging from never showing an agitated behaviour (1 point) to several times an hour (7 points). The 29 behaviours were selected on the basis of previous literature as well as nurses' perceptions and include: pacing, inappropriate robing or disrobing, spitting, cursing or verbal aggression, constant requests for attention, repetitious sentences or questions, hitting, kicking, grabbing, pushing, making strange noises, screaming, scratching, trying to get to a different place, general restlessness, complaining, negativism, handling things inappropriately, hiding things, hoarding things, tearing things, performing repetitious mannerisms, verbal sexual advances, physical sexual advances, intentional falling, throwing things, biting, eating inappropriate substances, and hurting oneself or others (Cohen-Mansfield et al. 1989).

In one study, ratings on the CMAI were compared to those for the Behavioral Syndromes Scale for Dementia (BSSD) and the Behavioral Pathology in Alzheimer's disease (Behave-AD) with a cohort of 232 'elderly patients' living in a long-term facility (Finkel 1992). This study took an interrater (or intra-observer) approach to assess the reliability of the CMAI, which involves having two or more observers independently applying the instrument with the same people and then the observer's scores are compared (McHugh 2012). The interrater reliability was calculated using 20 pairs of researchers on a set of randomly selected residents across three shifts; day, evening and night shift. The interrater reliability (intra-class correlation) for the total score for the CMAI tool was 0.41. Interrater reliabilities were also calculated for each of the subtypes of agitated behaviours and were 0.66 for physical aggression, 0.26 for physical non-aggression, and 0.61 for verbal agitation. According to Finkel (1992) the results show that this inventory can be a valid and reliable scale to evaluate the agitation in patients with Alzheimer's disease. However, when using interrater reliability measurements, there is a

general agreement that the value of 0.60 is minimally acceptable and that values of 0.75 or higher are very good (Polit and Beck 2017; McHugh 2012). Taking this agreement and looking at the results of this study it could be said that only the subtype of verbal agitation achieved an acceptable interrater reliability score. The interrater score for the CMAI tool overall was 0.41, which suggests that there were more disagreements than agreements among the 20 pairs of researchers, which questions the reliability of the tool.

One of the reasons I am presenting this material is to show how much research energy has been put into attempting to monitor and manage 'behaviours' in persons living with dementia. There are other assessment tools, which are used by caregivers through observational assessment and interactions with persons living with dementia (*table 2*). The majority of assessment tools used to measure the frequency and severity of various behaviours use a point-scoring system and do not involve the person with dementia. Therefore, these instruments only reflect the assumptions of the investigator, as what is 'behavioural' and/or 'inappropriate' is a highly subjective concept. Additionally, what could be burdensome to one person could be completely un-troubling to another. Even further still, these assessment tools do not involve the person living with dementia and do not encourage the caregiver to discover what is going on in the world of the person living with dementia to have a deeper understanding of their emotional needs. They do not consider why someone might be expressing themselves in a certain way. The majority of these tools were developed 20-30 years ago when dementia was regarded as a mental health condition and the assessment tools seem to be based on this assumption. It is no surprise that people with dementia were not included in the research associated with the development and use of assessment tools. However, as previously stated, there is an expectation that people living with dementia should now be involved as far as possible within research and healthcare decisions. By including people who live with dementia in research, we can have a deeper understanding about how they are feeling and develop a way to assess personal expressions that involve the person. Thus, if we have an assessment

tool/model which allows healthcare professionals to gain more in depth understanding of how persons with dementia are feeling and how they are perceiving their world and others within it, we will undoubtedly have a better understanding about their personal expressions, which will enable healthcare professionals to offer support that is person-centred and to respond appropriately and sensitively to them.

Therefore, I argue that 'behavioural' assessment tools only go as far as/in describing patterns of personal expressions, but even at that, these instruments are dependent on the caregiver conducting the assessment. Additionally, each of the assessments tools appear to have been built on the assumption that displays of emotion and feelings are unnatural and are a result of having a dementia. Even though these assessment tools claim to be used specifically for persons living with dementia, anyone and everyone has emotions, senses and desires and will express themselves according to their feelings, sensations and pleasures. The clear difference is persons without a dementia diagnosis, or any cognitive impairments are usually able to articulate through language their emotions and reasons behind their 'behaviours', or even constrain any sign of emotions altogether. I argue that changes in someone's verbal communication skills should not be an excuse to suddenly view natural personal expressions in a biomedical paradigm and it gets treated like a symptom of a condition. Later in this chapter I will discuss more in-depth on how responding to someone's expressions should not be viewed as a 'problem' or a 'challenge', but an opportunity to have a deeper understanding about how someone with dementia is feeling and to provide person-centred care.

So far in this chapter, I have introduced the concept of BPSD, its origins and how it has developed since 1996. I have discussed my struggles in finding the relevant evidence base behind the creation of BPSD and have highlighted that with the advancing knowledge on dementia and the shift towards person-centre care, the psychiatry model of BPSD is considerably outdated and there is the need to move away from a positivistic paradigm with its the biomedical approach. I have also brought attention to the various assessment tools and have reviewed one of the

most used tools in assessing 'behaviours' in people living with dementia. The following section will explore how 'behaviours' or personal expressions have been and is still currently 'managed' within dementia care then I will move onto my reflections section for this chapter.

The Biomedical Perspective of how to Respond to Personal Expressions

As mentioned earlier in this chapter, there was a huge push from the IPA and various pharmaceutical companies to conduct research on the use of medications, such as antipsychotics to 'treat' BPSD. In more recent times, there has been a significant effort to approach BPSD by using non-pharmacological practices in persons living with dementia (Bird et al. 2007; Kales et al. 2012; Scale et al. 2018). However, even though current local, national, and international policy suggest that pharmacological interventions should be used as a last resort, it seems that the biomedical view that personal expressions from people living with dementia should be minimised or stopped using medication is still apparent even today. It is well documented that there is not only a limited amount of evidence of the benefit of psychotropic medications for persons living with dementia (Sink et al. 2005), but the use of antipsychotics is associated with higher risks of myocardial infarction and other cardiovascular issues (Pariante et al. 2012; Douglas and Smeeth 2008; Savva et al. 2009). There is also a higher rate of mortality associated with persons living with dementia who are prescribed antipsychotic drugs (Kale et al. 2012). Due to the limited evidence on the benefits of medications for BPSD the UK based National Institute of Health and Care Excellence advises that:

'people with dementia who develop non-cognitive symptoms or behaviour that challenges should be offered a pharmacological intervention in the first instance only if they are severely distressed or there is an immediate risk of harm to the person or others'.

(NICE 2015)

However, current literature (White et al, 2017; Bjerre et al. 2018; Child et al. 2012; Kales et al. 2015) suggests that it is still common for older persons living with

dementia to be prescribed antipsychotic medications to manage 'behavioural symptoms'. This is despite the drive a few years ago coming after a parliamentary inquiry (Banajee report) that calls for the reduction of antipsychotic prescribing for persons living with dementia. A study, conducted by Walsh et al. (2016) aimed to compare the use of psychotropic medications in people with and without a dementia diagnosis, who were who were admitted to acute hospitals. Results showed that persons with dementia were significantly ($p < 0.001$) more likely to be prescribed psychotropic medication than persons without dementia (Walsh et al. 2016). Additionally, this study discovered that persons with dementia were more likely to experience psychotropic polypharmacy, which meant that they were prescribed two or more psychotropic during the same period of time, than those living without dementia (Walsh et al. 2016). These statistics are quite frightening, however, unsurprising due to the common knowledge that persons living with dementia are usually prescribed antipsychotic medications if they express themselves in ways that others deem inappropriate. A longitudinal study exploring the 'management of BPSD' in two acute hospitals within the UK found that antipsychotics were prescribed for 12% of patients with dementia who had a 'documented BPSD' (White et al. 2017). What is interesting is that of the people that had a prescription for an antipsychotic, 70% of the prescriptions were new on admission to hospital (White et al. 2017). A hospital setting can be an uncomfortable and frightening place for anyone and many people, with and without dementia, and they express emotions of anxiety and fearfulness. However, because someone with dementia might not be able to have a firm control over their emotions and might not be able to understand clearly the environment that they are in and the people they are interacting with, they express their feelings of distress much more clearly and obviously than perhaps someone without a dementia diagnosis. These expressions are a normal response to feelings of uncertainty and vulnerability, and if anyone were put into a situation that they could not understand or felt scared we would be expressing these feelings. Due to the fact that the biomedical view of BPSD views expressions of distress as

unnatural, problematic and a symptom of dementia, it is viewed that it must be 'treated'. However, if we embrace personal expressions it gives healthcare professionals an opportunity to really understand how the person is feeling and why they are feeling anxious, scared or apprehensive etc. Therefore, instead of trying to 'fix the problem' or make the problem disappear by medication, we can understand the world that they are perceiving with empathy and compassion, and this can enable people with dementia to receive better support.

Powers (2017), an internationally recognised educator and specialist in caring for people with changing cognitive abilities, has challenged what he calls the 'Pill Paradigm' in dementia care. He argues that reducing the use of psychotropic drugs in the symptomatic treatment of dementia is key to successfully implementing compassionate, person-centred care. In his book, *Dementia Beyond Drugs* he challenges the biomedical position of BPSD and the use of drugs to respond to personal expressions (2017 p. 29-52). Powers states that there is real neurological damage of the brain of people living with dementia, and as a result the person may be less able to cope with stressors, and control over certain situations. They may even need to rely on alternative communication pathways. However, he reassures his readers by stating that the neurological changes are not the root cause of distress, and 'drugging the brain is not the solution'. Powers (2017) argues that practitioners prescribe antipsychotic drugs because they do not have, or more accurately, are not aware of a more effective alternative and feel expected to provide a pill to 'solve the issue'. The following paragraph reiterates this claim by focusing on two research studies that highlight how general practitioners (GPs) view their own practice with regards to 'managing BPSD'.

In 2011, Buhagiar and colleagues explored the confidence and knowledge of general practitioners (GPs) regarding the identification and management of BPSD. The GPs, who were practicing in Ireland, were asked to fill in a self-assessed questionnaire. Findings showed that despite the fact that GPs have a wealth of knowledge about BPSD, they are largely critical of their knowledge on their management skills of BPSD. Although many GPs (92.5%) highly valued the important role of non-

pharmacological interventions in BPSD, none of them reported recommending these in their daily practice. This study is insightful in regard to understanding that GPs are unlikely to suggest therapeutic approaches to 'managing BPSD', however, it fails to give any rationality as to why GPs have difficulty in recommending non-pharmacological approaches. Seven years later, a further study was conducted by Jennings et al. (2018) exploring GPs experiences when 'managing' BPSD in Ireland. Rather than sending self-assessed questionnaires, Jennings et al. (2018) interviewed sixteen GPs, to establish their challenges when supporting persons with dementia and their management decisions concerning BPSD. This study found that GPs felt under pressure to prescribe antipsychotic and sedative medications, instead of recommending non-pharmacological interventions to manage BPSD. Reasons for not encouraging non-pharmacological interventions included a lack of clinical guidance, stretched resources and complying with the expectations from family, carers and nurses (Jennings et al. 2018).

The literature highlights that psychotropic medications are still predominantly used within our healthcare system for persons living with dementia who express themselves in ways that could be viewed as culturally and societally 'inappropriate'. Even though the use of pharmacological sedatives still seem to be the 'go-to' methods in order to respond to personal expressions, there has been without doubt an inflation of research and literature advocating the use on non-pharmacological interventions for the 'management of BPSD'. According to Scales et al. (2018) non-pharmacological interventions include a whole range of practices such as sensory practices (e.g. aromatherapy, massage, bright light therapy), psychosocial practices (e.g. pet therapy, music therapy, reminiscence therapy, meaningful activities), structured care protocols (e.g. bathing, mouth care) and are more effective than psychotropic medications for the treatment of BPSD. Backhouse et al. (2016) conducted an ethnographic study within four care homes to explore the use of non-pharmacological interventions to 'manage BPSD'. Findings showed that non-pharmacological interventions improved the resident's quality of life. However, the recommendations from this study is that non-pharmacological approaches should

replace administering antipsychotics and other sedative medications to 'control' the behaviours of persons living with dementia. Therefore, all that has truly happened is that we have replaced a possibly harmful intervention with various activities and psychosocial interventions. This could be regarded as a positive step, however, the underlying principle that personal expressions are regarded as unnatural, problematic and a 'symptom' of dementia remains true within this model of care.

Further still, Scales et al. (2018) argues that non-pharmacological approaches to address BPSD are person-centred. Even though non-pharmacological approaches are an improvement from psychotropic and other sedative medication prescriptions, this does not go far enough in the ambition to achieving person-centred care. In fact, non-pharmacological interventions just 'papers over the cracks' of the BPSD model as the development of these interventions originate from the behavioural lens associated with BPSD. Non-pharmacological interventions have only somewhat replaced the use of medications and even though the use of meaningful activities or various therapies are a step in the right direction with regards to the ambition of de-prescribing, personal expressions are still viewed as problematic and as a symptom of BPSD. By adopting the view that personal expressions are a 'symptom' of having a dementia it is unsurprising that these expressions are seen with the need to be 'managed' in some way. I argue that we need to reframe how we view, assess and respond personal expressions, in a way so that we can understand the world that they are perceiving and how they are feeling. To conclude this review, I am now going to share my personal reflections on how personal expressions are viewed, and why we need a new direction away from BPSD.

My Personal Reflection

In the previous section, I explored both pharmacological and non-pharmacological interventions associated with BPSD and have argued that these interventions and responses to personal expressions do not achieve person-centred care. Coming from a perspective where embodiment and our emotions, senses and desires are fundamental to personhood, I argue that people with dementia are expressing what

they are perceiving and how they are feeling in a certain moment in time, and their expressions are not a behavioural aspect as a result of their dementia diagnosis. For this section I want to expand on this viewpoint by sharing some of my thinking and reflections that has occurred while reading literature around BPSD and 'inappropriate behaviours'.

Reading about the origins of BPSD, its evolvment and how it has dominated dementia care has ignited many questions and concerns about BPSD and how people living with dementia are perceived and cared for. While exploring the evidence for this review I couldn't help but constantly refer back to my philosophical underpinnings and strikingly I could see that many authors and researchers ascribe to a person-centred approach or perspective and yet uncritically refer to or work with BPSD model. Much of these questions arose when I was reviewing the various assessment tools that were developed to monitor the 'behaviours' of people living with dementia, especially the CMAI. Two questions that I have been pondering over during this review is: (1) what is *'inappropriate'* agitation and (2) why is agitation an *'inappropriate behaviour'* for someone living with dementia?

To help answer these questions, I have been thinking about myself, a person without a diagnosis of dementia, and thinking about times when I get 'agitated'. This could be a number of situations in which I feel the slightest bit uncomfortable, or even a little vulnerable such as, just before I'm about to stand up and speak in front of public or when I am in an unfamiliar environment for the very first time, like when I have been admitted to hospital. Feelings of agitation can be dealt with and communicated in many different ways. When someone is 'agitated' they might fidget with their anything they can get a hold of, such as a pen. Many people are unable to sit still and feel the need to move their bodies as their adrenaline builds up and they need to release their energy in some way. Some people might talk very quickly and ask the same question repeatedly as the answer might not have registered with them. Other people are more likely to swear or raise their voice when feeling vulnerable, and if they feel in any way threatened people might want

to or actually become physically aggressive. Some may cry in times of feeling stressed, and some will want to retrieve themselves from others during this time. Personally, when I feel agitated or apprehensive, I become fidgety and I want to exclude myself from others so I can be on my own to gather my thoughts. I have also been known to cry when feeling very nervous and uncomfortable. The point I want to make here is, if someone was observing me prior to speaking in public, or if I was in an unfamiliar environment and people I didn't know kept talking to me, there would be no doubt I would score high on the CMAI. However, because I am able to articulate the reasons behind my 'expressions', it is highly unlikely I would be classified as displaying 'inappropriate', 'challenging' or 'disturbing behaviours' and therefore, unlikely that I would be prescribed an antipsychotic to manage my feelings and behaviours.

Then I thought of people living with dementia and when they might be feeling agitated or apprehensive. I immediately thought of my nursing practice and when I have cared for people with dementia who were deemed as having a 'challenging behaviour' and in need of psychosocial interventions and/or antipsychotics. I took a step back and imagined if I had just entered a healthcare setting without any recognition to what a hospital or a nursing home is or why I was there. I imagined a busy place with many strangers talking to you or touching you. People are constantly rushing around, and it can feel claustrophobic and difficult to make sense of. It is not usual to feel lost in a healthcare environment or to lose someone. The various noises of people talking, telephones ringing, the nurse call buzzers and different machines beeping can be very overwhelming. The smells can be overpowering, and it can be a difficult environment for sense making. I reflected on my healthcare experience on being admitted to hospital. Even though I had no cognitive impairments, and I could make sense and understand the situation I was in and my surrounding environment, I was still very nervous, upset and in need of reassurance. However, due to the effects on their memory, judgement and other cognitive abilities, a person with dementia might not feel familiar or have an understanding of their surroundings, including the environment and the people

around them. They also might not be able to communicate through the use of language how they are feeling and experiencing their environment in that moment in time. For example, in healthcare settings they could be getting spoken to or touched by people they do not know, or they might not realise that the person touching them is a nurse who is there to provide care. I took a moment to imagine how I might feel and react if someone I was unfamiliar with was trying to direct me to somewhere I did not know or if they were constantly asking questions that I could not understand. It is not unnatural to feel threatened or vulnerable when someone we do not know speaks or touched us. I might cry or be more unlikely to cooperate if I did not trust the person speaking or touching me. There are many different ways that I might react in ways that would classify me as being 'agitated' and showing signs of distress when I am feeling vulnerable. Persons living with dementia are no different. However, because someone with dementia might not communicate their thoughts through language that others understand, what they are feeling and thinking, their actions get labelled as 'meaningless', 'non-compliant', 'challenging' and 'inappropriate'.

There is always an underlying meaning to the way someone is expressing themselves. No bodily movement or expression from someone living with dementia is meaningless; they are responding to what they are perceiving and how they are feeling. The fact that the person might not be able to articulate the reasons behind their actions is not an excuse to label them as 'challenging' and/or 'inappropriate' and to offer psychotropic medications or psychosocial interventions. I discovered an inspiring quotation from Lao Tzu (also known as Laozi or Lao-Tze), an ancient Chinese philosopher that seems fitting for this chapter. Lao Tzu famously said:

'If you do not change direction, you may end up where you are heading'

When it comes to personal expressions in people living with dementia we are still on a BPSD pathway that is heading towards a biomedical approach that suggests we much manage and minimise expressions from people with dementia. To provide person-centred care, we do not only need to change the way we address personal

expressions, but we need to change direction away from the viewpoint of the BPSD model to a destination that values the way people living with dementia express themselves. By adopting the philosophy that emphasises the importance of our embodiment and how bodily emotions gives us meaning we can value and have a deeper understanding of personal expressions displayed by persons living with dementia. To creatively capture my thoughts and reflections, I wrote a poem about my critical challenge of BPSD and the current evidence of sexual expression in older persons living with dementia, which is underpinned my behavioural assumptions, which I discuss more thorough in Chapter Five. This poem can be seen in *Appendix 1*.

Conclusion

In this chapter I have discussed the issue of BPSD in dementia care, in the form of a critical review. I have explored the creation and the developments of the BPSD model that has dominated dementia care and places natural, personal expressions as a 'symptom' of dementia. Following on from understanding the background to the formation of BPSD, I reviewed how 'challenging behaviours' were assessed. This section highlighted that the various assessment tools were problematic in that they are based on the assumption that dementia is a mental health condition and they rely on caregivers interpretations of 'behaviours' and what they view as problematic. They also do not attempt to offer insight as to why someone with dementia might be expressing themselves in a certain way. I have also discussed the use of pharmacological and non-pharmacological interventions that healthcare professionals are using in response to personal expressions and have put forward an argument that this does not achieve care that is underpinned by person-centredness.

To conclude this chapter, I discussed my personal reflections on the concept of BPSD and how it disagrees with my values and my philosophical position. I reflected about times where I have had feelings of agitation, anxiety and/or apprehension in order to show that these emotions are natural responses to when we are in situations that are different, unfamiliar and make us feel vulnerable. I argue that we

all experience emotions and feelings, as it is a natural part of life and of being a person. We are all different in the way we experience the world, our environment and our interactions with others and we are all different in the way we respond to situations that trigger strong emotions and feelings. Thus, there will be no magic one pill or psychosocial interventions that fits all. Emotions are key in helping us to assess and monitor what we are perceiving and help us to gain meaning of our world and our interactions in it. Personal expressions are responses to how persons living with dementia are feeling in regards to what they are perceiving. The fact that persons living with dementia are at times unable to communicate through language, is not a valid reason for denying that emotions are meaningful. We need to be creative and to offer a new approach that allows us to understand what people with dementia are perceiving and that will give us a deeper understanding to why they are expressing certain emotions. Once we have this understanding we adapt to their needs and wishes and can provide more person-centred care for persons with dementia.

Chapter Four: The Sensuous Framework

Introduction

As someone who identifies themselves as a person-centred researcher and a nurse, I could not progress this study whilst BPSD was the main, and arguably the only, theoretical backdrop for sexual expression. In this chapter, I am introducing and defining two ideas that will be very helpful for an alternative way of thinking about sexual expression in persons with dementia. I will suggest that 'sensuous' and 'expressing sensuousness' are more applicable for persons living with dementia. By conducting an etymological exploration of sensuous and sensuousness, and through reconceptualising I will introduce a new framework, 'The Sensuous Framework'. This framework shows personal expressions stem from our bodily emotions, senses and desires and therefore, expressions are never meaningless or 'behavioural'. This chapter will introduce a new way of looking at personal expressions and how with a combination of my philosophical position and the critique of BPSD, a new theoretical framework emerges. To begin this chapter, I am going to share with you my own personal reflections of how my thinking has reached this point.

My Personal Reflections

Through engaging with the literature surrounding BPSD and sexual expression in persons living with dementia and by having critical conversations with my supervisory team, we have been exploring and discussing the notion of 'bodily communication'. Bodily communication is the use of physical expressions and mannerisms to communicate nonverbally, often done instinctively rather than consciously (Domenico 2013). Whether you are aware of it or not, when you interact with others, you are continuously giving and receiving wordless signals (Domenico 2013). When persons with dementia have a decrease in cognitive ability and linguistic communication skills, they are sometimes unable to articulate what they are perceiving, feeling and thinking, so they use other forms of communication, such as using their bodies to express themselves (Domenico 2013;

Kontos 2002), like when persons with dementia are expressing their sexual needs and desires. With that said, this got me thinking about times and situations when people living with dementia may be expressing themselves and others mistakenly label the expression as 'sexual'. For example, a woman with dementia who is removing her clothes and holding her breast may have breast or even cardiac pain. Or a man who is taking off his trousers and touching genitalia could possibly have groin or testicular pain. However, both these scenarios could be mistakenly interpreted as masturbation and touching themselves for self-pleasure. The removal of clothes in itself can often be mistaken for sexual intent, but could easily mean the person is uncomfortable, doesn't like what he/she is wearing, needs to use the bathroom, or perhaps they would like to be naked, but may express these feelings before the person tries to articulate these feelings.

If the underlying meaning of such actions and expressions were clear to us, then the action suddenly becomes appreciated and respected. There is nothing bizarre and unnatural about someone holding a part of their body that is tender or in physical pain or removing their clothes if they need the toilet or wanting to go to bed. The sensations of certain textures against the skin for people living with dementia can change or feel different, and sometimes they don't recognise what they are wearing or feel uncomfortable in the clothes that they are in, so they remove the clothes to feel comfortable, without necessarily realising they are in a public space such as the lounge in a care home or a hospital ward. Again, it can be clear to see why this may be mistaken for an example of 'sexual expression.' Or, if the underlying meaning is sexual, and a person is pursuing to get sexual pleasure, it is also understandable why someone may want to remove their clothes and touch their or another persons' body. There could be many explanations of what others may consider to be sexual expression, but it is just a way of communicating an emotion or feelings. However, more often than not, the meaning behind personal expressions are not clear and the person gets labelled as 'behaving inappropriately'.

Our culture and society have conditioned us to believe that there is a certain time and place for us to display particular emotions and respond to how we are feeling

(Allwood 2002). Cultural norms have informed us that specific actions that display strong emotions and desires, for example, having a cry if we are upset or touching our own or others intimate body parts in public spaces is inappropriate. Therefore, we learn to suppress the strong emotions and desires we experience, until we are in a place or a situation where it is 'appropriate' to do so. We have been adapted to cover up our bodies, especially body parts that are considered to be private such as breasts, buttocks and genitals. In my experience and throughout my lifetime, those 'private body parts' are not only perceived as 'private', but are one's 'sexual body parts', which must be kept hidden under clothing, and if exposed publicly it is viewed as inappropriate.

I started to reflect on bodily expressions and ways of communication between two people. I thought about the simple, yet multidimensional, expression of a handhold. A hand-hold with a friend can be a way to express ones need for comfort or reassurance, whereas a hand-hold with a lover can represent intimacy and sexual desire; it's the same act, but the feelings, sensations and/or pleasures behind them can completely vary. Additionally, these two reasons for a hand-hold could be with the same person or with different people. Then I started thinking about a hug or a cuddle, which involves more bodily contact between two people and can be a form of communication for many different reasons. I asked myself: *'in recent times, how many people have I hugged or cuddled and why? What was the reason and feelings behind the hugs?'* To provide a short answer, I have hugged (and received hugs) from a number of people, for various different reasons, whether it's a way of greeting someone, a way of saying goodbye, a 'friendly hug', a 'well-done hug', an 'intimate-hug', a 'comforting-hug'. Each of these embraces is a bodily communication or expression and provides the same action in which you wrap your arms around someone. So, from the outside world another person may mistakenly interpret the action of a hug, as they do not understand the meaning which is behind that embrace. In other words, there are so many different feelings, reasons and scenarios which could be associated with embracing another person and connecting with them in the form of a hug. Therefore, the meaning of the

expression does not come from the action itself, it stems in part, from the persons emotions, senses and desires.

I think it is important at this point to emphasise that I am not saying that every time a person with dementia expresses themselves, it is always perceived by others as being sexual or the underlying meaning is always sexual. Neither am I saying that all bodily expressions are non-sexual. What my aim is by reflecting on the experience of a handhold and a hug, is to highlight that one act can have multiple meanings, messages and is very context-bound. Thus, what I am arguing here is that this is how all personal expression in persons living with dementia needs to be viewed. There needs to be an appreciation that no action or expression is a direct result of having dementia, or a 'behavioural symptom of dementia'. All personal expressions, whether that is displaying feelings of anger, joy, grief, frustration, love or sexual desires stem from our unique emotions, desires and our senses, and can vary depending on the context and the situation.

In Chapter Two, I put forward my belief in that persons living with dementia are no different to any other human being in that they are embodied beings who experience emotions, desires and senses and it is through experiencing emotions, desires and senses in which they make sense of the world. Therefore, this chapter will offer an original framework that offers a fresh perspective and demonstrates how when people with dementia express themselves. When persons with dementia are expressing themselves, they are expressing their emotional response to what they are perceiving. They are expressing their authenticity. At times, some of the expressions of persons living with dementia is not covered up or diluted by rational thinking or what society tells us to believe what is right or wrong. I agree with similar positions of theorists such as Kontos (2012) and Hughes (2001) in that our embodiment is core to our personhood, they are invaluable to our meaning-making capabilities which need to be recognised in relation to people living with dementia.

I am going to call this original theoretical framework, 'The Sensuous Framework' as the concepts have strong connections to the fundamental emotional and sensory

aspects of our human experience. Throughout my philosophical explorations and discussions with my supervisory team, the word 'sensuousness' and 'sensuous' would often be articulated, but I would hear and use this word without having an understanding of its meaning. In the next section, I am going to explore key aspects of the history and developments of sensuousness and how it has been positioned until now. I will offer a new definition for this framework. Despite my research focusing on one aspect of human experience or one 'type' of personal expression, sexual expression, this framework has the potential to offer a person-centred alternative to the BPSD model. In the section following the description of the development of the Sensuous Framework, I discuss how sexual expression relates to this new position and how from this, the final research aim has emerged.

[Sensuousness: Moments from History](#)

Exploring sensuousness has been a challenging process as the use of sensuousness and sensuous within a nursing context is arguably negligible. Additionally, where there is the use of sensuous in nursing literature, meanings and definitions behind 'sensuous' seem to vary significantly, or the meaning of 'sensuous' is not clear when it is being used. Thus, it is important for me to be clear in with my definition of 'sensuous' and 'sensuousness' and for this to be transparent throughout this thesis. Before I set out these definitions, I am going to offer a historical outline in the English language, of sensuous. It will become clear very quickly that to get a sound grasp of the meaning of sensuousness, I had to step into other professional domains and subject areas to draw upon their work on sensuousness, namely English literature.

I initially began this etymological exploration with a quick Google search and immediately Google offered me an alternative search question. Interestingly, Google asked, 'did you mean sensual?', so I decided to look at both words in more depth. Very quickly I realised there was divide about the meaning of sensuous. On one hand, the word 'sensuous' and 'sensuousness' is sometimes used interchangeably with 'sensual' and 'sensuality', which conveys meanings relating to sexual desires and pleasures. On the other hand, 'sensuous' is sometimes, and was

historically used, to relate to bodily sensations and pleasures that were explicitly non-sexual. To understand sensuous more broadly, I first explored etymological descriptions:

The English Oxford dictionary defines 'sensual' as:

'Relating to or involving gratification of the senses and physical, especially sexual, pleasure.'

The English Oxford dictionary defines 'sensuous' as:

1. *'Relating to or affecting the senses rather than the intellect.'*
2. *'Attractive or gratifying physically, especially sexually.'*

The Cambridge Dictionary defines 'sensuousness' as:

1. *'the quality of affecting or relating to the physical senses, rather than pleasing the mind or the intelligence.'*
2. *'the expression or suggestion of physical, especially sexual, pleasure or satisfaction'*

When using the English Oxford/Cambridge dictionary's definition, it is clear to see that the words sensual and sensuous are frequently used interchangeably to mean 'gratifying the senses,' especially in a sexual sense. However, according to Stein (2015) this goes against its traditional meaning, by which sensuous is a more neutral term, meaning 'relating to the senses rather than the intellect'. For example, listening to classical music can be a beautiful, sensuous experience. Whereas 'sensual' relates to gratification of the senses, especially sexually. In fact, the word 'sensuous' is thought to have been invented by John Milton in 1641, in a deliberate attempt to avoid the sexual overtones of sensual and to describe the gratification of senses and emotions in a neutral sense (Stein 2015). However, much of the time the connotations are such that it is difficult to use sensuous in Milton's sense as much of the use of 'sensuous' suggests sexual pleasures.

The Oxford English Dictionary cannot find any evidence of the use of the word by any other writer for 173 years, not until Samuel Taylor Coleridge popularised it:

'Thus, to express in one word what belongs to the senses, or the recipient and more passive faculty of the soul, I have reintroduced the word sensuous, used, among many others of our elder writers, by Milton.'

(Coleridge, 1987)

Nevertheless, sensuous was not popularised until the 18th century. There are some useful pathways within English poetry and literature, specifically writings during the 18th century that have explored sensuous. Doody (1999) shows us that 'sensuousness' can be found within the work of 18th century women writers, particularly poets, and she argues that it is the most directly sensuous poetry that England has ever had. The women poets brought alive a sensuous world that was often ignored by other (male) poets and philosophers. Doody (1999) argues that the women poets of the 18th Century, such as Ann Yearsley, Mary Leapor, Mary Robinson, Anna Seward and Anna Laetitia-Barbauld, were not reluctant to explore the activities of sensing and the sensuous world. It is believed that the publication of Locke's *Essay Concerning Human Understanding* brought some unease amongst other authors and poets, especially as his concluding position is especially close to that of Descartes (Doody 1999). Locke (1964) argues that we have no contact with the real world out there; the world is all in our minds. However, the women poets present us with a clearly sensuous world and claim that the mind cannot be divorced from the senses. They often expressed sensuous by writing about our shared sensuous with animals and imaginative species, such as elves and fairies. What is unique and important for this research here is not the relation between humans and animals, but how the senses are given its place in meaning making. The important message in the 18th century poetry is how the female poets emphasise the importance of our senses in our ability to feel connected to the world. They argue that when there is an emotional connection, there is a felt sense of belonging. The women poets can offer an avenue to show that our emotions,

senses and our desires are in fact, what brings us meaning to the world. In other words, meaning arises from our sensuous aspects of life (Salami 2020).

This was written at a time in history in which historians, philosophers and scholars of English literature have classified as the 'sensibility movement' (Wickberg 2007). Sensibility in today's world is related to the ability to be rational, reasonable and/or practical. In today's language, for someone to be a 'sensible person' one uses their cognitive intelligence and morality to make informed decisions and to adhere to societal norms. However, traditionally it was defined as the quality of being able to appreciate and respond to complex emotional or aesthetic influences; our sensibility (Wickberg 2007). The sensibility movement provided a challenge and a different school of thought to those thinkers who believed in *a priori* concepts, that is, knowledge that exists independent of experience.

A key text within the sensibility movement, was none other than Jane Austen's 'Sense and Sensibility' (1811). This romance novel tells the tale of two sisters, Elinor and Marianne, whose approach to life, love and relationships were very different. The novel highlighted a comparison of a person using their cognitive intelligence (sense) compared to someone who approaches life using her emotions, feelings and desires (sensibility). Both sisters deal with the notions of joy and heartache within the novel. One of the sisters, Marianne, was very expressive of her emotions and made her decision based on how she felt:

'Marianne was silent; it was impossible for her to say what she did not feel.'

(p. 118)

When Marianne experiences her heartache, she did not override her emotions and made it evident to how hurt and grief-stricken she felt:

'The evening passes off in the equal indulgence of feeling'.

(p. 83)

In comparison, when Elinor experiences heartbreak she ended up concealing her feelings and emotions:

'She was very far from wishing to dwell on her own feelings... Elinor was to be the comforter of others in her own distress, no less than in theirs'.

(P.244-245)

Throughout the novel, Elinor appeared the stronger of the two sisters and the one who would be more likely to succeed in finding a husband as she did not display her emotions and kept the 'correct' social etiquette. However, towards the end of the novel Elinor experienced joy and delight, when she discovered that the man who she had affection for, Edward, did not enter a marital relationship with another woman. He unrepentantly turned up and proposed to Elinor, and even she could not conceal her true emotions and desires when Edward claimed his love for Elinor:

'Elinor could sit no longer. She also ran out of the room and as soon as the door was closed, burst into tears of joy, which at first she thought would never cease'

(p.335)

This shows that emotions are deeply rooted in everyone and at times the ability to reason our emotions is challenging and near impossible. For Elinor, a woman who used her cognitive intelligence and her sense *over* her sensibilities, this rationality was then broken down when she felt overwhelmed with joy, relief and happiness. In other words, her emotions 'bet' and overcame her sense in the particular scene. It was like her emotions over spilled this barrier she had up until this point.

It has been debated amongst historians and scholars of English literature whether or not Austen herself agreed with the sensibility movement and valued the expression of strong emotions (BBC Radio 4: In Our Time 2002). Some reviewers believe that Austen values our sensuous experience through our

emotions, senses and desires, and thinks that Marianne becomes the stronger character as the novel progresses as through her sensibility, she has she has stayed true to her emotions is more in tune to herself. On the other hand, many critics have seen the novel as a critique of the 'cult' of sentimentalism prevalent in the late 18th century (Wickberg 2007). The sensibility movement was often criticised for encouraging persons to be self-indulgent with their feelings and some critics have said that Austen praises Elinor for concealing her emotions and drawing upon her rationality more often than expressing her sensibility. Whether Austen believed in the sensibility movement and used her writing to argue that people should fully be in touch with sensibility, or not, is left for historians and scholars of English literature to debate. For the purpose of this chapter, I want to focus on the fact that Austen recognised that emotions, senses and desires are alive within us and is part of who we are as human beings and that sometimes, no matter how hard we try to let our cognitive and analytic thought defeat our sensuous intelligence, we cannot overcome our authentic emotions and desires (Vermeir and Deckard 2011).

However, since the 18th century and the work of scholars and novelists of the sensibility movements, we have significantly moved away from recognising our sensuous capabilities much to our detriment. By focusing on attributes such as analytical thinking, rationality and morality, we have forgotten the purity and richness that our sensuousness can bring to our lives (Damasio 1999). We seem to have lost the significance of our purest emotions, intimate senses and deepest desires. We need to reinforce some lessons that the scholars of the sensibility movement have to offer us. Together with my philosophical position, which is essentially sensuous, and the work of the sensibility literature, I can reconceptualise sensuous and sensuousness, give it a modern twist and develop a framework that works for this research so that we can celebrate our initial sensuous perception of the world (Serres 2009). According to van Ede:

'A renewed interest in the senses, then, leads to an intensified methodology, and inherently towards critical reflection on the ethical aspects of all

scientific practices that concern human beings, and the epistemology it stands for. It compels us to reconsider who is in the power position to decide what true and valuable knowledge is, and for whom.'

(2009 p. 62)

So far in this chapter, I have discussed my desire to develop a new sensuous way of viewing personal expressions through an embodiment worldview, where our human ability to experience emotions, senses and desires are recognised and celebrated within dementia care practice and literature. Following on from my reflections, I have briefly outlined the etymological journey that sensuousness has taken throughout English literature and called for sensuousness to be revitalised. In the next section, I will take this idea forward and offer a redefinition of sensuous and sensuousness, a definition that aligns with my values and beliefs around personhood and person-centred dementia care. Then I will use this reconceptualisation of sensuousness and create a tentative theoretical framework for personal expressions in persons living with dementia, and specifically for this research, sexual expression in persons living with dementia.

The Creation of my 'Sensuous Framework'

Definitions surrounding sensuousness have been few and far between and too often misused or mistaken for sensuality (Stein 2015). In my view, 'sensuousness' has been poorly defined of previous scholars has not grasped the full potential that sensuous and sensuousness can offer. For example, some speak of sensuous and sensuousness as purely relating and paying attention to the five senses (Serres 2009), which is important and our senses absolutely contribute to our perception and how we interact with our world around us. On the other hand, I feel that sensuous should not be limited to our five senses of sight, hearing, smelling, tasting and touch. In my perspective, our sensuous capabilities incorporate all our emotions, senses and desires which are fundamental for our being and interaction within the world and ways of gaining meaning in our lives.

When we experience powerful feelings, sensations and/or pleasures we are in touch with, what I am going to call, the 'sensuous' aspects of who we are as unique individuals and what we are experiencing within the world around us. When we *feel* sensuous, we respond in a way to express and gratify our emotions, senses and desires. How we respond, express and gratify our feelings, sensations and/or desires is what I am going to call our 'sensuousness.' Therefore, sensuousness is our expression of our sensuous capabilities. The way I am defining 'sensuous' is:

'Our ability to experience, our emotions, senses and/or desires through our feelings, sensations and/or pleasures respectively.'

What I believe this definition of sensuous achieves is that it incorporates all bodily emotions, takes into account our natural senses and acknowledges our deepest desires. Sensuous is our experience of our emotions, senses and desires. It is the process of emotions, senses and desires coming alive to us through our feelings, sensations and pleasures. The expression of our sensuous is what I am calling 'sensuousness'. Sensuousness is the outcome or the action that persons do in response to our sensuous experiences. The way I am defining 'sensuousness' is:

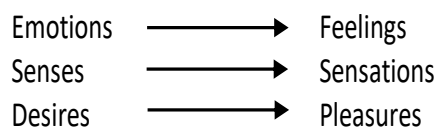
'The gratification and/or expression of our emotions, senses and/or desires'

So, I have now provided a new definition for both 'sensuous' and 'sensuousness'. However, I want to set out clearly, with the help of a visual, how I imagine the journey our emotions, senses and desires take to giving us a sensuous experience and how we express our sensuousness. In other words, I want to show the relational aspects of all these different concepts and how they connect with one another. This will then be the beginning of a tentative theoretical framework that will demonstrate the way persons express themselves and how they are genuine responses to our natural emotions, senses and/or desires.

Referring back to my philosophical underpinnings, I envisage we experience our sensuous capabilities when our emotions, senses and/or desires become conscious to us through our feelings, sensation and/or pleasures respectively. By drawing on the ideas of philosophers and scientists who have recognised our existence as

human beings is embodied (Merleau-Ponty 1962; Johnson 1999; Dewey 1981; Damasio 1999), I argue that we cannot forget the role our emotions, senses and desires has in our ability to create human understanding and meaning. Focusing in on the relation between emotions and feelings, emotional responses can occur long before we become aware we are *feeling* and emotion (Damasio 1999). Emotions and emotional responses can operate beneath the level of consciousness and feelings are our conscious awareness of our emotions and the feeling of an emotion is the principle way that a person becomes aware of changes in his or her body (Johnson 1999). Even though the relationship between senses and sensations, and also between desires and pleasures, have not been given the same in scientific literature and philosophy, I believe there are similarities in their connections. Sensations are our conscious awareness of our senses, and our pleasures are our conscious awareness of our desires. In Chapter Two, I presented these relationships and ideas as linear (*figure 6*).

Figure 6: Experiencing our Emotions, Senses and Desires Through Feelings, Sensations and Pleasures.

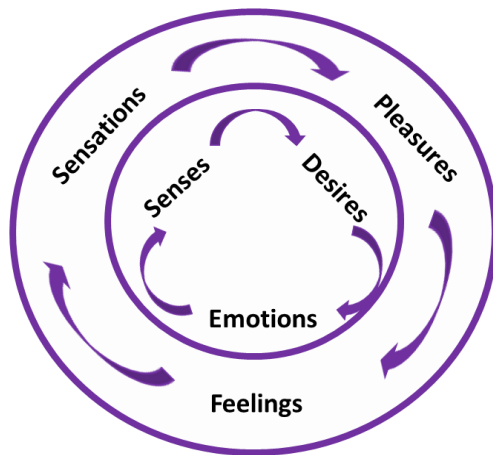


As much as *figure 6* demonstrates how we feel the aliveness of our emotions, senses and desires, I now feel it has two major flaws. Firstly, this image does not covey the idea that our emotions, senses and desires are interconnected and dynamic. They all work together and influence one another to give value to our experiences. For example, what we see may evoke a certain emotion and in turn, an emotion may influence what we see and how we perceive a situation. If we desire something, we will feel a various amount of emotions based on whether we gain pleasure, or displeasure if we do not gratify our desires. Our senses may ignite or supress our desires. For example, smelling freshly baked bread may enhance our

desire for food. Or an intimate touch from a lover may evoke sexual desires. Feelings, sensations and pleasures are always in relation. They are fluid and always dynamic.

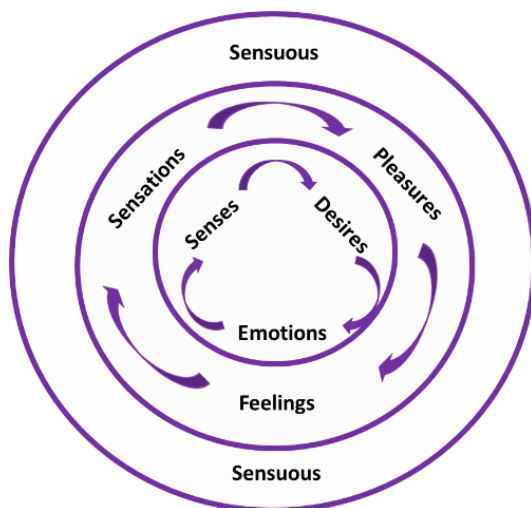
The second flaw I now see is that I viewed these aspects of human existence like a cause and effect relationship which is too quantitative and analytic. Rather, I envisage our special ability of tapping into our emotions, experiencing our senses and being aware of our desires (through feelings, sensations and pleasure) should be viewed as an added layer to who we are as persons. I then thought that this whole idea about how we express ourselves, and how our sensuous stems from our emotions, senses and desires can be seen as layers. Rather than layers of cake where different levels of sponge, jam, cream and icing are stacked up on top of each other, I see sensuousness like layers of an onion, where you have a 'core' central part and then the following layers surround and build upon the core. Our emotions, senses and desires develop into a new level, or rather a new layer closer to our bodies' surface where we experience our feelings, sensations and pleasures. Without our 'core' emotions, senses and desires we would not be able to experience feelings, sensations and pleasures. Feelings, sensations and desires are not resulting, they are an added layer to what lies within our core as individual persons. These layers should not be viewed as levels and fixed. Rather they are dynamic, vibrant and uncongealed. *Figure 7* reveals the way I am representing the relationships between emotions and feelings, senses and sensations, and desires and pleasures after addressing the two major flaws with my original representation. In my perspective, *figure 7* now clearly gives the perception that our emotions, senses and desires are separate entities, nevertheless, they are in constant and dynamic relation with each other. The image also illustrates that our emotions, senses and desires become alive to us through the added layer of our feelings, sensations and pleasures.

Figure 7: Emotions, Senses and Desires Evolve into Feelings, Sensations and Pleasures.



Thinking about the definitions of sensuous and sensuousness which I presented at the start of this section, I reconceptualised 'sensuous' as our ability to bodily experience our emotions, senses and desires through our feelings, sensations and pleasures. Through our feelings, sensations and pleasures our sensuous world becomes alive to us. We experience a way of knowing that no abstract thinking can provide us. We are connected to the world, to each other through our sensuous experience. This definition shows that all persons are sensuous beings as we all experience emotions, senses and desires, yet each person will experience the sensuous in ways that are unique that person. The physical aspect seems important and connected to bodily expression or of the flesh (Salami 2020). No two persons are the same, and a significant element of that is due to the fact that we experience emotions, senses and desires in unique individual ways. Thus, if our 'core' is personalised and unique to who we are as our own person, then so too will our sensuous be personal to everyone. Therefore, taking my redefinition of 'sensuous', I see sensuous being the next layer in this image, surrounding feelings, sensations and pleasures (*figure 8*).

Figure 8: Adding the Sensuous Layer



I am now going to introduce the final layer to my framework. The outermost layer is called 'expressing sensuousness' (*figure 9*). This is the layer that is exposed to the rest of the world. It is expression of our sensuous. This is the skin of our emotions, senses and desires, where we respond, express and/or gratify them. For example, when we experience grief some reach out for a hand to hold, when some experience anxiety our bodies fidget and start to shake. The way we express our sensuousness could be a smile we cannot erase when we are fulfilled with joy or the sparkle in one's eye when someone is in-love. The satisfying notion we get when we taste the creamiest chocolate, or the fulfilment in our hearts with the sound of the music we love gets put on repeat and makes our bodies move to the rhythm of the beat. This is what we express to others and the rest of the world. Expressing sensuousness is what others see when they look at individuals.

With this said, I think it is important at this point to briefly touch on the fact that many of us have the ability to 'control' and enforce a barrier between the sensuous and the expressing sensuousness layer. When persons develop their cognition and rationality, persons have the ability, however sometimes only to a certain extent, to filter what we are expressing to the world and to others. Some people are better at this than others. Some feel comfortable displaying their sensuousness, others like to

put up a strong barrier between how they are feeling and what they are expressing. Part of this is due to our own vulnerability and that we do not want to show the world our true selves (Stanghellini and Rosfort 2013). It is also about taking responsibility for what we reveal and share and what we want to keep private and known to us and not others (Sabat 2002). How we have adapted culturally and within our society also has a role to play in this sensuous barrier persons can put up. We are conditioned from a young age to learn where is 'appropriate' to be emotional, to do certain activities that gratify our sensuous experiences, therefore we can control, suppress and/or delay our sensuousness for when it is 'right' to do so. This becomes a crucial point in the next section when thinking about persons living with dementia whose cognitive ability has declined and they no longer have the ability to impose such a strong barrier between their sensuous and expressing sensuousness. Emotions, senses and desires may come to the foreground and may be more likely to be bodily expressed as cognitive and particular linguistic expression falls away. Sometimes we only seeing bodily expressions as the outermost, visible layer without understanding the crucial sensuous layers underneath it.

Figure 9: Expressing Sensuousness

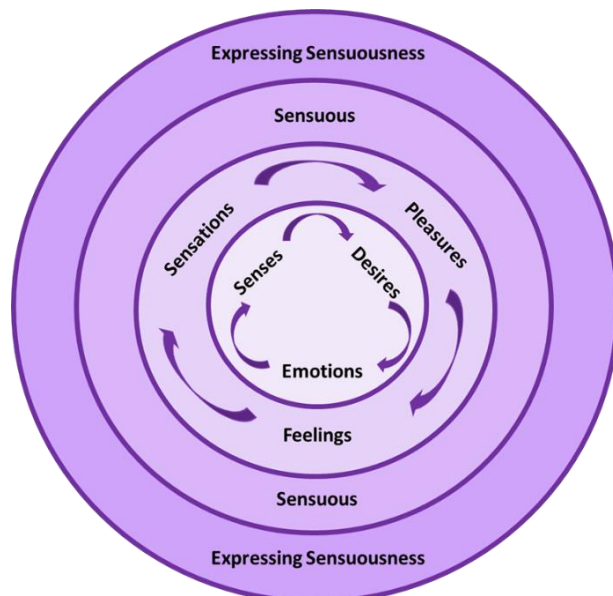
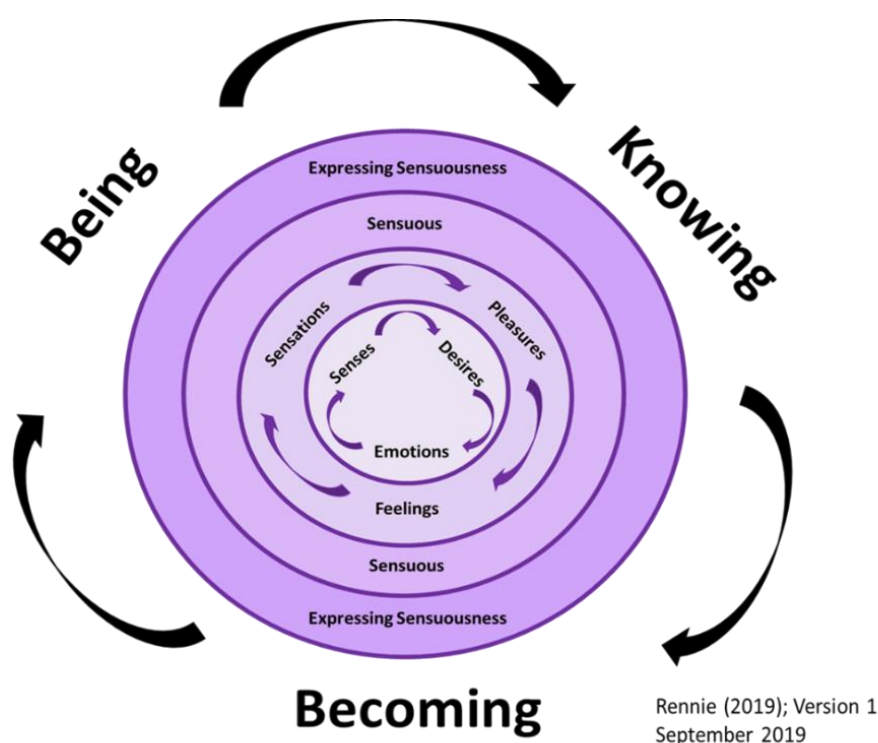


Figure 9, now elucidates my thought that being in touch with our sensuous capabilities and how we express our sensuousness, is being in touch with our emotions, senses and desires. The expressing sensuousness illustration clearly demonstrates that emotions, senses and desires are the core of who we are and how they influence how we interact with others and our world around us. Through our bodies, and our ability to experience our emotions, senses and desires we create meaning and as they transform into our awareness through our feelings, sensations and desires we are able to consciously know the meaning of an experience or situation. Our sensuous capabilities are making our being-in-the world alive to us. In other words, persons are sensuous beings. Our sensuousness is part of our being, informs our ways of knowing and is dynamic and ever evolving. This is summarised nicely as we are not simply rational and mental beings, we are emotional and physical beings (Salami 2020). For example, in persons whose cognitive capabilities are declining the emotional and physical ones will come to the fore. The being-knowing-becoming cycle which I discussed in Chapter Two appreciates that persons are never static; we are in a constant state becoming. Our sensuousness is never static either, it is dynamic, every changing and thriving. Our sensuous capabilities and expressing sensuousness strongly relate to my perception on our being, knowing and becoming. My ontological beliefs which I described in Chapter Two, along with my values surrounding epistemology and transformation, present strong connections with this re-conceptualisation of sensuous and sensuousness. Knowledge can be accessed and assessed through our connection to the emotions, senses and embodied experience (Salami 2020). Thus, I now see the expressing sensuousness image more than just a diagram; I see it as a tentative theoretical framework. *Figure 10* shows the Sensuous Framework.

Figure 10: The Sensuous Framework



The Sensuous Framework, although tentative, is a useful and even essential theoretical foundation to drive my research forward. It has emerged from combining my philosophical tenets, which are shaped by my values and beliefs on personhood, together with my critique of BPSD presented in Chapter Three, and my re-conceptualisation of sensuous and sensuousness. I have created a provisional framework that offers a new perspective on how to understand persons with dementia and at the same time, as it is the antithesis of the BPSD model, it fundamentally challenges the ideas underpinning BPSD. In the next section I can going to discuss the relationship between sensuousness and sexual expression.

[The Relationship Between Sensuousness and Sexual Expression](#)

Now I will focus in and discuss how sexual expression relates to the Sensuous Framework and how the Sensuous Framework is a much more suitable and person-centred theoretical backdrop to viewing sexual expression in persons living with dementia. I am going to conclude this chapter by envisaging how I see this research

moving forward with a new framework. As I mentioned at the start of this chapter, when looking at 'sexual expression' specifically, the expression can be 'sexual' or 'non-sexual', even the exact same expression. Therefore, there needs to be an understanding from the person living with dementia on what they are perceiving and feeling, as there needs to be an approach to 'sexual expression' that aims to understand what the person with dementia is perceiving and feeling in that moment in time. Perhaps, at times, we focus too much on what we are interpreting on the outer layer of someone's sensuousness without delving into the invisible, yet fundamental layers beneath that are within us. Potentially, it is not enough to place judgement and assumptions on someone's personal expressions based on other's interpretations. Seeing persons as sensuous beings and understanding all our sensuous experiences we have as persons can offer a different perspective to people's expressions and has the potential to provide more sensitive, person-centred care.

Considering how much nurses deal with bodies and bodily functions; sexual expression is not as evident in nursing literature and texts as might be supposed (Lawler 1991). In ageing and dementia care for example, sexual expression is still more commonly presented as abnormal and wrong with term such as, 'inappropriate sexual expression', 'sexual disinhibition' or 'hypersexuality' used to describe the way persons living with dementia who express themselves. These words/phrases amongst others that are much more disrespectful, reveal the underlying way in which older persons and especially persons with dementia are viewed culturally when it comes to sexual identity and expression of that identity. Persons living with dementia and nurses must socially negotiate the various norms, values, taboos, beliefs, and learned ways of behaving with respect to the body, which need redefinition in the context of reduced individual independence (Lawler 1991).

Sexual bodily expressions and ways of communicating through the body encompass a wide range of gestures, movement and actions (with or without verbal input) that express needs and desires, which may include any of multiple types or levels of

sexual ideas and feelings. Bodily expressions can easily be mistaken as sexual when the underlying meaning is completely non-sexual. Further, general sexual expression is often misinterpreted by others as being directed at them when it is not. When people experience a decline in cognitive ability, such as persons living with dementia, the world becomes a much more sensory and intimate place, and people are more likely to respond and express what they are sensing and feeling, and use their bodies to make sense of their emotions (Twigg 2010). However, what others see is only the expression from the person and often the true reason is misinterpreted.

The Sensuous Framework does not fragmentise emotions and desires of a sexual orientation away from all other emotions and desires. We are more comfortable with other emotional and desirable aspects of our human experience, but this cannot be a reason for us to ignore or separate the significance of our sexual experience and who we are as sexual beings. Sensuousness presents us with an opportunity to embrace all sensuous feelings, senses and pleasures that our experience has to offer us. It allows us to see personal expressions in persons living with dementia in a new light, in a way that their authentic emotions, senses and desires can be respected and admired. Sensuousness provides a new perspective in which we see personal expressions as a result of pure emotions and desires. Throughout this chapter, I have been clear about how we need to understand the true emotions, senses and desires behind each expression and have a greater understanding about what people living with dementia are feeling and perceiving in the moment. This allows us to move away from a behaviouristic perspective of natural human experiences.

To reiterate, it is important at this point to emphasise i) that I am not claiming that every time a person with dementia expresses himself or herself that it is always perceived by others (e.g. nurses) as being sexual or ii) that all bodily expressions are non-sexual. There is a domain within sensuousness that does include overt sexual expression and some of this is problematic. This research is interested in the domains of sensuousness that are perceived by others as sexual and inappropriate,

although are not about overt, illegal sexual acts. What this study intends to show, by viewing sexual expression through the lens of sensuousness, is to highlight that one gesture, movement or act can have multiple meanings and is very context-bound. Nurses are well placed given their connection to bodies and bodily functions to have a more dynamic and fluid view on sexual expression. This will enable other people to understand the older person living with dementia and respond appropriately to them and their needs. This research will be the first to explore bodily expressions through the lens of sensuousness within nursing.

There are times and situations when a person is expressing their sexual needs and desires, and responses are often insensitive and guided through the principle that sexual expression is a 'symptom' of dementia. Therefore, expressions that are sexual need to be explored to reframe 'sexual expression' in a person-centred way. What I am suggesting is that the way people express themselves needs to be understood at bodily level and what emotions, sense and desires are alive which result in the person expressing themselves.

With the Sensuous Framework now being my lens that is shaping and guiding my research, I feel it is worth revisiting my aims of this research. Originally my research aims were as follows:

- To gain knowledge on meaning of sexual expression in persons living with dementia in a nursing home setting.
- To explore how sexual expression in persons living with dementia is understood by nurses working in the nursing home.

I feel that a third point now needs to be added to the research aims. I want to now explore sexual expression through the lens of sensuousness within the research. I want to know how personal expressions are felt at bodily level with persons living with dementia, and how sexual expression relates to sensuousness. Not only will the Sensuous Framework, assist me with my synthesis and findings of the research, but from this chapter onwards, my entire research journey will be explored through the lens of sensuousness. The way I view the literature I engage with from now on

will be critiqued through a sensuous vision. Additionally, my methodology and methodological principles will emerge from the position of the Sensuous Framework. The presence of sensuousness will be strongly felt throughout my fieldwork and how I synthesise and present the findings, until the end of this research. Sensuousness needs to be represented and felt in my aims of this study. Therefore, I added a third aim to this research:

- To explore the relationship between sensuousness and sexual expression.

Conclusion

In summary, I have introduced a new theoretical perspective that could have the potential to change how we view and respond to persons living with dementia and how they express themselves. I have presented the concepts sensuous and sensuousness, with new definitions, to clarify how I interpret our emotional aspects of being. With the development of sensuousness, I have fused together my reconceptualisation of sensuousness together with my philosophical position to create a tentative theoretical framework, The Sensuous Framework. Sensuousness is unique because it sees emotions, senses and desires as a whole, and does not detach the sexual aspects of our lives. Furthermore, sensuousness argues no expression of our emotions is due to symptoms of dementia. By default, this means that the framework in this chapter challenges BPSD. This tentative framework will allow me to continue my research and exploring sexual expression in persons living with dementia through a coherent theoretical framework that is itself embedded in a person-centred worldview and within my philosophical beliefs.

I want to conclude this chapter with a poem that I wrote, which grasps the essence of sensuousness. I wrote this poem at the beginning of this chapter, when the ideas of sensuousness first arose. I kept this poem close to me throughout the developments of this chapter and the research for inspiration. It brought me back

to the heart of my idea, provided me with focus, and kept the passion going within me to creating the Sensuous Framework.

Sensuousness

To touch an emotion

The warmth of laughter.

The power of a gaze,

Being connected – feeling exposed.

A kiss from the autumn breeze,

against a soft cheek.

The ocean,

a source of tranquillity.

The sensuality of silk caressing the skin

A lovers embrace,

the pleasure of flesh.

Layers of desire.

Chapter Five: A Literature Review on Sexual Expression in Persons Living with Dementia

Introduction

Up to this point in the thesis, I have discussed in depth my philosophical and theoretical position that is providing the backdrop to where I place my research. Now that I have set the scene to the research it is time to refocus to the topic of sexual expression and this starts with an exploration of the current literature and review what knowledge is currently known on this topic. This chapter provides a literature review of the existing evidence around sexual expression in persons living with dementia. It took a while to get the focus of the literature review to a level that was meaningful and informative, yet manageable. Initially I aimed to conduct a literature review which provided an overarching view on sexuality in older persons, sexuality in nursing in general and cultural perspectives on sexual expression, as well as focusing on persons living with dementia specifically. However, this proved to be a challenge as literature which was collated from 'sexuality in older persons' and 'sexuality in nursing' was vast and had the potential to drift away from the main focus of this research. The areas of 'sexuality in older persons' and 'sexuality in nursing' are important areas which would benefit from a rigorous review in future work. Additionally, there was a lack evidence that explored cultural perspectives on sexuality in older persons. This highlights the need for future research and publications that focuses on diverse cultural experiences of sexuality in older persons.

I then focused on sexual expression in persons living with dementia within a nursing home context only. However, the pendulum swung the other way and the review became too narrow as research which has taken place in nursing homes focusing on sexual expression is limited and the search results does not yield a strong comprehensive review. To prove a richer understanding and review, I expanded this literature review to look at the experience of sexual expression in persons living

with dementia, cultural perspectives of sexual expression and how nurses view and care for persons living with dementia.

Therefore, this literature review serves three purposes. Firstly, I explore the importance of sexual expression, sexual satisfaction and intimate relationships in persons living with dementia. Secondly, this chapter aims to understand the cultural perspectives of sexual expression involving persons living with dementia. Finally, to situate the research focus within the extant literature and provide justification for this specific research, I focus on how sexual expression is understood and experienced by nurses working in nursing home. My immersion in the literature extended for about six months at the start of the research process. I repeated the literature search annually throughout the research.

Method: Searching the Literature

The evidence supporting this literature review was found through the traditional routes of searching academic databases. A literature review seemed most appropriate for this piece of work as it aims to critique and evaluate published materials that provide examination of recent or current literature (Grant and Booth 2009). A Literature review covers wide range of subjects at various levels of completeness and comprehensiveness, allowing to examine a broader scare of evidence (Grant and Booth 2009). For this literature review, I used the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) guidance (Moher et al. 2009), which aims to help authors improve the reporting of systematic reviews, meta-analysis and literature reviews.

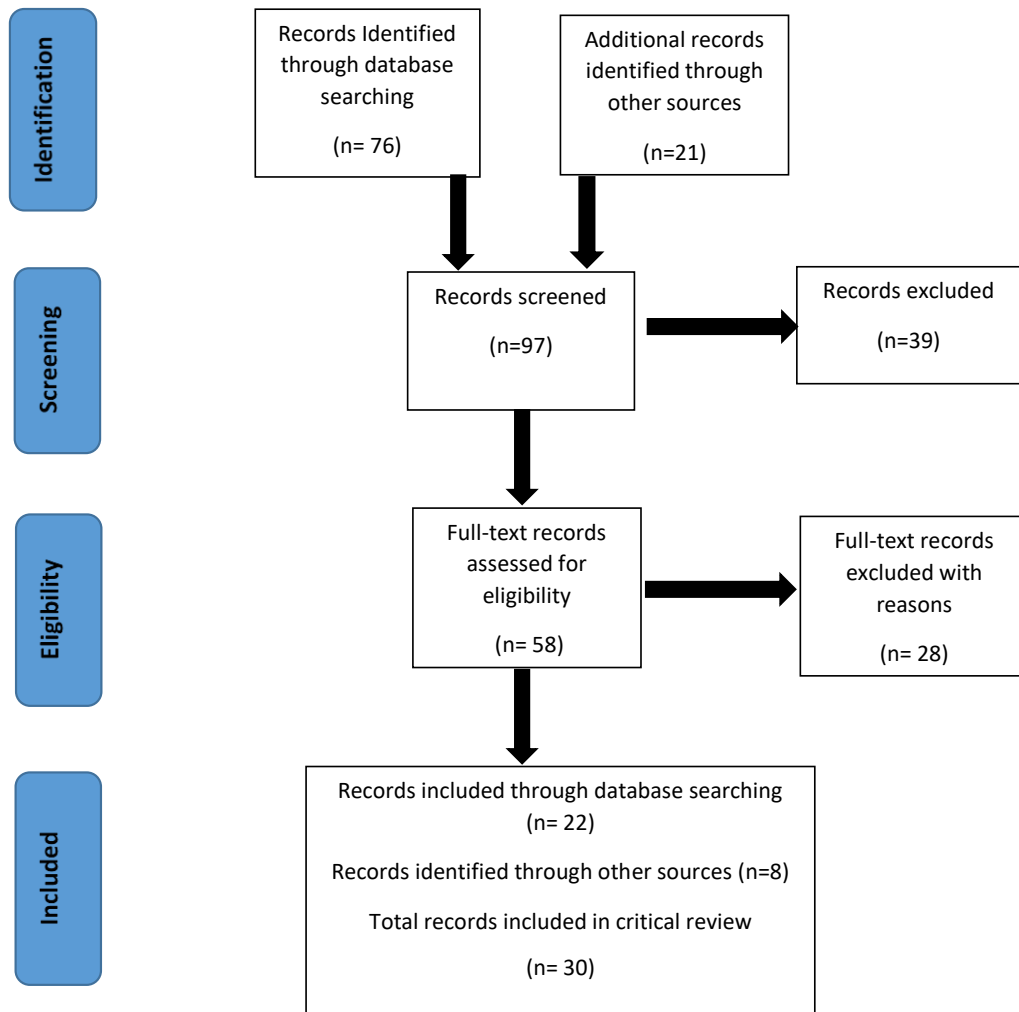
Searches for literature included but was not limited to academic databases to find relevant research on sexual expression in persons living with dementia. The databases that were used to locate some of the articles included in this review were CINAHL, PsychINFO, Medline and Science Direct. The key search terms used for the data base searches were, 'sexual expression', 'sexual intimacy', 'intimate relationships', 'sexual behaviours', 'inappropriate sexual behaviour', 'problematic sexual behaviour' and 'hypersexuality', in combination with, 'dementia', 'persons

living with dementia', and 'dementia care'. When using the word 'behaviour', both the UK and the American spelling were used so that articles with either spelling could be located. The inclusion criteria for this review was:

- Articles that explores the importance of sexual expression and/or sexual/intimate relationships in persons living with dementia.
- Publications that explored cultural perspectives of sexual expression and/or sexual relationships in persons living with dementia.
- A focus on the care of older people with dementia in relation to sexual expression and sexuality in all care settings.
- Papers published from 2000-2020.
- 'Full-text' with references was available.
- Written in English.

A total of twenty-two papers that explored sexual expression in persons living with dementia, to some degree, were found through searching the online databases. A further eight pieces of evidence was collated through hand-searches of journals and reference list. This resulted in gaining a total of thirty publications which was included in the review (*see figure 11*). From these publications four themes emerged: (1) the importance of sexual expression and intimacy in later life and in persons living with dementia; (2) cultural perspectives of sex and intimacy in later life and in persons living with dementia; (3) nurses perception and experiences of sexual expression and (4) assessing and responding to sexual expression in persons living with dementia.

Figure 11: PRISMA for Sexual Expression Literature Review



Importance of Sexual Expression in Persons Living with Dementia

Sexual expression is a fundamental aspect of who an individual is and their overall well-being, throughout the whole life span (Bauer et al. 2013). Benbow and Beeston (2012) argue that sexuality in later life, especially those living with dementia remains a neglected topic, but state that attention to sexual expression has the potential to contribute to the quality of life of people living with dementia and their caregivers. However, our society tends to perceive older adults as asexual who no

longer has sexual or intimacy needs, and research focused on health problems and sexual dysfunction in later life encourages the stereotype that older people do not, cannot, or are not interesting in having any form of sexual relationship (Maataoui et al. 2017).

This review found some research that explored the sexual activity and satisfaction of people living with dementia and what effects having a diagnosis of dementia had on an long-term relationship (Davies et al. 2010; Dourado et al. 2010; Davies et al 2012; Nogueira et al. 2017; Fileborn et al. 2017; Sandberg 2020). Dourado et al. (2010) conducted a mixed-method study, looking at sexual satisfaction in people living with both mild and moderate Alzheimer's disease (AD), and their spouses. A total of 36 couples took part in the study and Dourado et al. (2010) found that 63.8% of people living with AD reported the presence of regular sexual activity in their relationship, whereas 55.5% of spouses claimed that there was a presence of sexual activity. These figures could, among other possible explanations, be due to misinterpretation of the question or participants holding different perspectives on what 'sexual activity' means. However, the same survey found that only 9.1% of persons with AD said that they were content and satisfied with their level of sexual activity. Additionally, a cross-sectional study, conducted in the United States (US) by Davies et al. (2012) found that over 70% of people with AD initiated a physically intimate activity with their spouse in the last month and the majority of people with AD maintained some of physical intimacy on a weekly basis. However, what people regarded as physical sexual intimacy ranged significantly between different individuals. The meaning of physical intimacy amongst the participants in the study included activities such as handholding, kissing, sexual contact and sexual intercourse. Similarly, Dourado et al. (2010) found that the meaning of sexual satisfaction differed amongst individuals, as 75% of the participants referred to sexual satisfaction as having sexual intercourse, whereas 25% associated sex with intimate affection. So, sexual satisfaction differed amongst couples, suggesting that 'sexual satisfaction' is subjective and individual.

In addition to a survey, Dourado et al. (2010) used follow up interviews to understand changes in sexual satisfaction, when someone in a long-term relationship is living with dementia. Even though 63.8% of persons living with AD reported regular sexual activity, many persons with AD and their spouses discussed that they felt dissatisfied with their sexual relationship with their partners. Nogueira et al. (2017) also explored the sexual activity of couples when a partner has been diagnosed with AD, and found that 67.6% of people with AD noticed a change in sexual activity and 36.5% reported severe dissatisfaction with this change. In comparison only 18.9% who claimed they were satisfied with their current sexual activity. Spouse-caregivers also reported that they noticed changes within their relationship, which altered their overall sexual satisfaction. According to Nogueira et al. (2017), 71.6% of spouse-caregivers reported changes to their sexual activity and 65% said that they were dissatisfied with their sexual relationship. Davies et al. (2010) found that marital couples, in which one person had a diagnosis of dementia, reported a decrease in affectional expression and sexual activity. Some couples reported this was because some felt they had lost reciprocity in their relationships, while spouses expressed feelings of emotional and psychological burden from being a caregiver and sometimes the lack of recognition as someone's long term partner was a turn off for spouses (Davies et al. 2010; Dourado et al. 2010). Much of the research exploring sexual activity amongst couples when one is living with a dementia suggests that couples have a decrease in both sexual activity and sexual satisfaction. However, the decrease in sexual activity may not be purely because of the dementia. Dourado et al. (2010) states persons with dementia are more likely to have other health issues influencing decreased sexual activity, such as heart disease and other co-morbidities. As persons get older there is also the increased risk of erectile dysfunction and vaginal dryness, which contribute to a reduction in sexual intercourse (Sanberg 2020). This suggests that a reduction in sexual activity and satisfaction is multifactorial, and it could be inaccurate to claim that a diagnosis of dementia alone results in reduced sexual activity.

Sandberg (2020) shows that sexual intimacy is important to both persons living with Alzheimer's disease and their partners. Sexual intimacy is a source of pleasure, comfort and recognition (Sandberg 2020). Many older couples, with one person living with dementia enjoyed sexual touching, caressing and cuddling as ways of being intimate. Any changes in couple's sexual relationship was attributed to normal ageing, rather than Alzheimer's disease (Sandberg 2020). For many older persons in Sandberg's (2020) study, intimacy was an aspect of life that did not feel different after an older person received a dementia diagnosis and provided the couple with connection and familiarity. There was a general finding that there was a move away from penetrative sex and continued to express their sexuality through more intimate and sometimes more meaningful expressions. Nevertheless, there was some sadness amongst couples that felt they could no longer talk about past pleasures and passionate memories with one another (Sanberg 2020).

Even though evidence suggest a reduction in sexual satisfaction amongst people living with dementia and their spouses, it is important to understand persons feel with changes to their sexual lives and how this has impacted on their overall wellbeing. Research claims that a reduction of sexual activity and intimacy is strongly correlated with feelings of sadness, loss and increased anxiety levels (Dourado et al. 2010; Bauer et al. 2013; Noguier et al. 2017; Simpson et al. 2018; Sandberg 2020). Dourado et al. (2010) found that men living with AD and spouses, generally associated sexual dissatisfaction with unhappiness, compared to women who reported feelings of lack of intimacy and increased anxiety. This supports the claim that sexual and intimate relationships contribute to overall wellbeing, Davies et al. (2012) found that couples with increased sexual satisfaction had greater levels of wellbeing and less emotional distress. These findings suggest that people living with dementia, who were included in these research studies, still value having intimate relationships and expressing their sexual identity.

For person's living with dementia residing in long-term residential care, the need and wishes to continue intimate relationships and to express their sexuality continues. Bauer et al. (2013) interviewed 16 residents living in a nursing home in

rural Australia, to explore their views for the needs and barriers of sexual expression. Five of these participants were living with early stages of dementia. Overall, residents including people living with dementia saw themselves as sexual beings and with a continuous need and desire to express their sexuality (Bauer et al. 2013). The participants highlighted the fact that sexual expression continued to matter, whether that be physical intimacy, companionship, sex or how one was socially presented, irrespective of whether they lived in a residential care facility or not. Connecting with this finding, Simpson et al. (2018) found that older adults, who are living with a care homes in the UK, missed 'being touched' in an intimate way. Many of the participants, both living with and without dementia, longed to be intimate with another person and would have welcomed the opportunity to be close with someone. There is a widespread view that people living in nursing and care homes still thought about sex, and moreover, it was recognised that this was perfectly natural to do so. Even when residents may not have been interested in sexual intercourse, it was clear that other expressions of sexuality were very important.

Cultural Perspectives of Sexual Expression in Persons Living with Dementia

Social and cultural norms are suggested to significantly influence how we view older persons and sexual expression in nursing care culture and practices, especially in long-term care settings (Yelland and Stanfield 2018). To reiterate, it became evident in the literature that there is a lack of focus on cultural influences on sexuality in persons living with dementia and older persons in general. Nevertheless, this review found two studies were found to explore the public perceptions and opinion on sexual expression in people living with dementia (Yelland and Stanfield 2018; Syme et al. 2017). Syme et al. (2017) conducted a content analysis on public comments, which were responding about a highly publicised legal case involving a husband engaging in sexual activities with his wife who has dementia and is living in a nursing home (Belluck 2015). All readers' comments were viewed in the light of the question, '*How does the public view sexual consent in the context of dementia in*

long-term care?' This study found that most of the public supports sexual expression for individuals with dementia with many agreeing how age and a diagnosis of dementia should not affect their ability to have some level of intimacy. However, 31.7% members of the public who responded demonstrated that they were clearly 'against' people living in nursing homes having sexual and intimate relationships, as they believe nursing homes should take the protective, paternalistic approach to caring for persons living with dementia. There was a view from the nurses that the resident living with dementia is a 'vulnerable person' who should be fully protected from any possible sexual exploitation as there was a fear that facilitating a sexual relationship could be causing harm. In comparison, Yelland and Stanfield (2018) looked at public perspectives of sexual relationships for residents living in nursing homes, focusing on newly formed relationships of residents, rather than existing relationships. This mixed-methods study, recruited 318 members of the public to take part in a quantitative questionnaire and to answer questions responding to a vignette which told the story of two people who developed a relationship with one another during their time living in a nursing home. After hearing about the new relationship, 78% of respondents indicated that staff members should attempt to stop the relationship between two opposite-sex residents with dementia who are not married to each other, regardless of whether the couple was engaging in flirtatious conversation or intimate physical intimacy (Yelland and Stanfield 2018). The degree or type of intimacy had no statistical bearing on attitudes (Yelland and Stanfield 2018). Thus, suggesting that the non-spousal nature of the relationships was a key reason for respondent's views rather than the degree of intimacy. However, it would be interesting to read and listen to comments from the general public when responding to a vignette about a couple who were married or long-term partners, prior to one of them being diagnosed with dementia to see if the concept of marriage conjures similar or different responses. Almost one-fifth of the respondents reported they believe that individuals with dementia lack the mental competency to experience intimacy and meaningful

relationships (Yelland and Stanfield 2018). One respondent, when asked about their perceptions of sexual relationships and people living with dementia wrote:

'I just know when you lose your mind you don't know what you are doing. I mean...it's just not right'

(Yelland and Stansfield 2018 p. 292)

These public perceptions contradict the small amount of evidence where persons living with dementia value intimate and sexual relationships, whether living at home or in residential care. This perception not only regards older adults living with dementia as asexual, but also tells us about societal perspectives of people living with dementia on a wider scale, beyond sexuality. Yelland and Stanfield (2018) reported that the majority of the public believes that staff should intervene and stop new, non-spousal intimate relationships occurring within a nursing or care home setting. In comparison, Syme et al. (2017) found that most members of the public were in favour of sexual expression for people living with dementia in care homes, and this should be part of care home policies. However, this study was in response to a married couple scenario who were continuing the relationships; it would be interesting to understand the thoughts of the public if it was a newly formed relationship. To understand the cultural position of this topic more fully an understanding on the public perception of older person's including those living with dementia, and sexual expression and relationships out-with a care setting would also be beneficial.

Research shows that policy concerning sexual expression in nursing homes is inadequate and ill-informed from both health services and the public's point of view (Yelland and Stanfield 2018; Syme et al. 2017). There is a clear need for more research to understanding on this topic to develop practice and policy. However, whether policies regarding the promotion and support to sexual expression in persons living with dementia in nursing homes should be established or not remains a conflicted debate amongst members of the public. This highlights that even from this small amount of evidence, is that there are still ageist and stereotypical

assumptions weaving through society that view persons living with dementia as vulnerable, in need of protection and not desiring to have an intimate relationship. Cultural perspectives need to change and the values and beliefs of persons living with dementia needs to be understood. The previous section emphasises that a lack of sexual and intimate relationships results in sadness and lower levels of wellbeing for persons living with dementia, but this is not understood fully within society. This suggests that it is not uncommon that personal beliefs and values among residents, family member and nursing home staff will differ (Yelland and Standfield 2018). Without research and policy guidance that incorporates the perspectives of persons living with dementia, personal biases from the families and nursing home staff may influence the decision-making process when it comes to resident's sexual expression (Syme et al. 2017), which has the potential to disregard the person's needs and wishes.

So far in this review, I have discussed the important of sexual expression and intimacy for people living with dementia. There is a general consensus within the published research that persons living with dementia maintain some level of sexual relationship, and what that means looks different for each individual. However, some evidence suggests that culturally this is not recognised and it is believed amongst many that persons living with dementia, especially if they are living in a nursing home, should not engage in any form of sexual relationship. For the next section, I will now focus on nurses' experiences of sexual expression and then how sexual expression is assessed in persons living with dementia and responded to within nursing home settings.

[Nurses Perception and Experiences of Sexual Expression](#)

Roach (2004) explored how nursing home staff viewed and perceived affectionate and sexual expressions of residents living in nursing homes. This study was conducted in both Australia and Sweden, to compare differing social and cultural areas, and to develop a more theoretically developed explanation about the phenomenon studied. Initially, the study was to only include nursing home staff from Australia, but Sweden was chosen as a comparison as it is known that sex

education had been compulsory in schools since the 1950s, and Roach (2004) wanted to see if that had an influence on the attitudes and beliefs of staff in a nursing home. Overall, staff perceptions and responses to residents' 'sexual behaviour' were found to be influenced by their own level of comfort related to sexuality issues, and the ethos within the organisational culture, which echoes the suggestion by Yelland and Stanfield (2018) and Syme et al. (2017) that culture and social norms influence nursing home practice.

Roach (2004) found that the interplay between personal sexual beliefs and organisational culture resulted in ways in which sexual expression is opposed or facilitated within nursing homes, which developed on the level of the comfort or discomfort of the nurse. Findings showed that Swedish nursing homes were more likely to experience positive outcomes for both residents and staff. Residents were able to express their sexuality freely and staff received education in a supportive environment and gained satisfaction from their relationship with the residents. Roach (2004) states that education surrounding sexuality and a positive cultural attitude to older persons and persons with disabilities or cognitive impairments were factors that contributed to some Swedish nursing homes being more positive towards sexual expression. Staff in the Australian nursing homes, who were aligned more towards a 'standing guard' theme found it easier to ignore any sexual expression rather than acknowledge the sexual needs of the resident and support them (Roach 2004). The majority of participants recognised an ageist culture within their workplace that saw 'sexual behaviours' as something relating to their dementia diagnosis.

Vandrevala et al. (2017) used interviews to explore nurses' perceptions and roles within the context of sexuality and caring for persons living with dementia. Eight nurses from two care homes took part in this study. The findings suggest that representations of sexuality in dementia held by nursing home staff ranged from the perception that sexual expression in old age was part of human nature and a basic right, to others that proposed that with the loss of memory and cognitive ability, people living with dementia experience a loss of interest in sexuality and

intimacy (Vandrevala et al. 2017). Similarly, Wiskerke and Manthorpe (2016) found that views of nursing staff ranged from recognising that sexuality is important to enhance wellbeing throughout life, to the reason for sexual expression is because of their dementia diagnosis and 'solutions' are needed in care home policies.

All the staff who took part in this study were comfortable with 'minor' forms of affection but thought it would be too challenging to deal with if the new relationship progressed into a sexual relationship. The staff responded that if the relationship was sexual, then they would need to observe, record, inform the local authority social services department, inform family members and the manager would need to hold a meeting (Wiskerke and Manthorpe 2016).

So far in this section, studies have suggested that sexual expression in persons living with dementia in nursing homes is perceived differently, depending on the views of the nurse and what type of sexual expression the person is displaying. In comparison, several studies have been found which discuss the experiences of sexual expression in negative and pessimistic terms (Hayward et al. 2012; Haesler et al. 2016; Tzeng et al. 2009). Tzeng et al. (2009) explored the 'characteristics of the contexts related to sexual behaviours among institutionalised residents with dementia'. This study found that nurses generally tended to ignore sexual behaviours as they felt uneducated to respond to sexual expressions. Additionally, Hayward et al. (2012) found through interviewing fourteen nurses and care assistants, that staff experiences feelings of shock and embarrassment was prominent when seeing and witnessing 'inappropriate sexual behaviour' from older adults living with dementia. Staff voiced feelings that they felt undereducated and had a sense of incomprehension in knowing how to respond to sexual expression in persons living with dementia. All participants reported discomfort and intense feelings of distress (Hayward et al. 2012). Likewise, Haesler et al. (2016) found that for many healthcare professionals, sexuality in older persons was an uneasy topic and that healthcare professionals expressed reluctance to raise a discussion about sexuality as it was beyond their scope of practice and that perceptions of sexual behaviour were viewed as problematic and influenced by the attitudes towards

sexuality. Healthcare professionals also expressed reluctance to raise sexuality during episodes of care and viewed sexual expression as problematic (Haesler et al. 2016). Further still, all studies in this review that explored nurses perceptions and experiences of sexual expression in persons with dementia, suggested that nurses felt undereducated and in need of some guidance when it comes to sexuality and dementia care (Haesler et al. 2016; Hayward et al. 2012; Roach 2004; Tzeng et al. 2009; Vandrevalla et al. 2017).

Assessing and Responding to Sexual Expression in Persons Living with Dementia

The previous section highlights that healthcare professional, in general, perceive sexual expression as challenging, and often feel inadequately trained to respond to sexual expressions. Bardell et al. (2011) found that ‘inappropriate sexual behaviours’ were identified as the chief complaint, amongst the 29 agitated behaviours (Cohen-Mansfield 1989) in clinical records. As sexual expression has been associated as a behavioural symptom of dementia, it has been widely accepted that sexual expression is an unnatural and a consequence of a dementia diagnosis in some individuals (Brännström 1996). Therefore, assessment tools for ‘challenging’ or ‘agitated behaviours’, which incorporate sexual expression, have been created within the biomedical perspective of BPSD. This literature review has yielded no results that show there are any assessment tools for persons living with dementia that focuses on sexual expression alone. Any assessment tool which has included sexual expression or ‘behaviours’ has been a small component of a much broader scale that looks to examine behavioural symptoms of dementia. *Table 3* shows a condensed list of the ‘behavioural’ assessment tools and scales that explicitly include ‘inappropriate sexual behaviours’ or ‘sexual disinhibition’ in persons living with dementia.

Table 3: Sexual Expression Assessment Tools

Tool Name	Author (Date)	Purpose of the tool	The tool's description on sexual expression.	How does the tool assess sexual expression?
Behavioral and Emotional Activities Manifested in Dementia (BEAM-D)	Sinha et al. (1992)	The BEAM-D Scale was developed for the operational assessment of troublesome and disruptive behaviours in dementia.	Sexually inappropriate behavior – touch, kiss, hug others in socially inappropriate settings, exposes him or herself, frequently (tries to) expose(s) self and masturbate(s).	Five point rating scale (0-4). 0 = No information: not assessed: unable to assess. 1= No sexually inappropriate behaviour observed. 2= Patient to touch, kiss, hug others in socially inappropriate settings.
The Behavioral Syndromes Scale for Dementia (BSSD)	Devanand et al. (1992)	The BSSD provides detailed examination of symptoms of behavioural disturbance.	Sexually proactive behavior such as making sexual advances.	Each item of the BSSD is scored with a 3 point scale, on the basis on both frequency and severity (0= No info; 1= Absent; 2= Minimal; 3= Mild; 4=Moderate; 5= Severe; 6= Extreme). The scale is used over a 1-week period.
Blessed Dementia Scale (BDS)	Blessed et al. (1968)	BDS was developed to assess an elderly person's ability to perform activities of daily living	Sexual misdemeanour (arising <i>de novo</i> in old age).	The BDS is split into three main sections: changes in performance of everyday activities; changes in habits; changes in personality, interests, drive. Each item in the changes in performance and the changes in personality (where sexual misdemeanour sits) is given one point if the item applies to the person being assessed.

<p>The Consortium to Establish a Registry in Alzheimer's Disease (CERAD) Behavior Rating Scale</p>	<p>Tariot (1996)</p>	<p>The CERAD Behavior Rating Scale was developed to provide a standardised method of evaluating the frequency (but not severity) of a wide range of pathological behaviours and psychiatric symptoms seen in patients with varying degrees of dementia. The scale should not be used if the persons with dementia is known to have a previous mental health history or those of have delirium.</p>	<p>Difference in sexual interests. Socially inappropriate things – e.g. sexually exposing self r done things such as making gestures or touching people inappropriately.</p>	<p>Each of the 46 items is scored based on the frequency of the behaviour. A score of 0, 1,2,3,4 8 or 9 can be given for each item. A score of 0 is given if the behaviour or symptom has not occurred since the illness began. 1 = the behaviour or symptom has occurred for 1-2 days in the past month; 2 = the behaviour or symptom has occurred for 3-8 days in the past month; 3 = the behaviour or symptom has occurred for 1-2 days in the past month; 4= the behaviour or symptom has occurred for 16 days or more in the past month; 8= the behaviour or symptom has occurred but not in the last month; 9 = Unable to rate.</p>
<p>The Cohen-Mansfield Agitation Inventory (CMAI)</p>	<p>Cohen-Mansfield et al. (1989)</p>	<p>To assess the frequency of manifestations of agitated behaviours in elderly persons in nursing homes. Later versions of the CMAI were developed for community use and a disruptiveness scale was added to each behaviour.</p>	<p>Making verbal sexual advances – sexual propositions, sexual innuendo, or “dirty” talk. Making physical sexual advances or exposing genitals – touching a person in an inappropriate sexual way, rubbing genital area, inappropriate masturbation, when not alone in own room or bathroom,</p>	<p>The CMAI is rated on a 7-point scale of frequency over a two week period, ranging from never showing an agitated behaviour (1 point) to several times an hour (7 points). Later versions of the CMAI added a 5-point disruptiveness scale as well as frequency scale of each agitated behaviour, which ranged from Not at all disruptive (1 point) to extremely disruptive (5 points).</p>

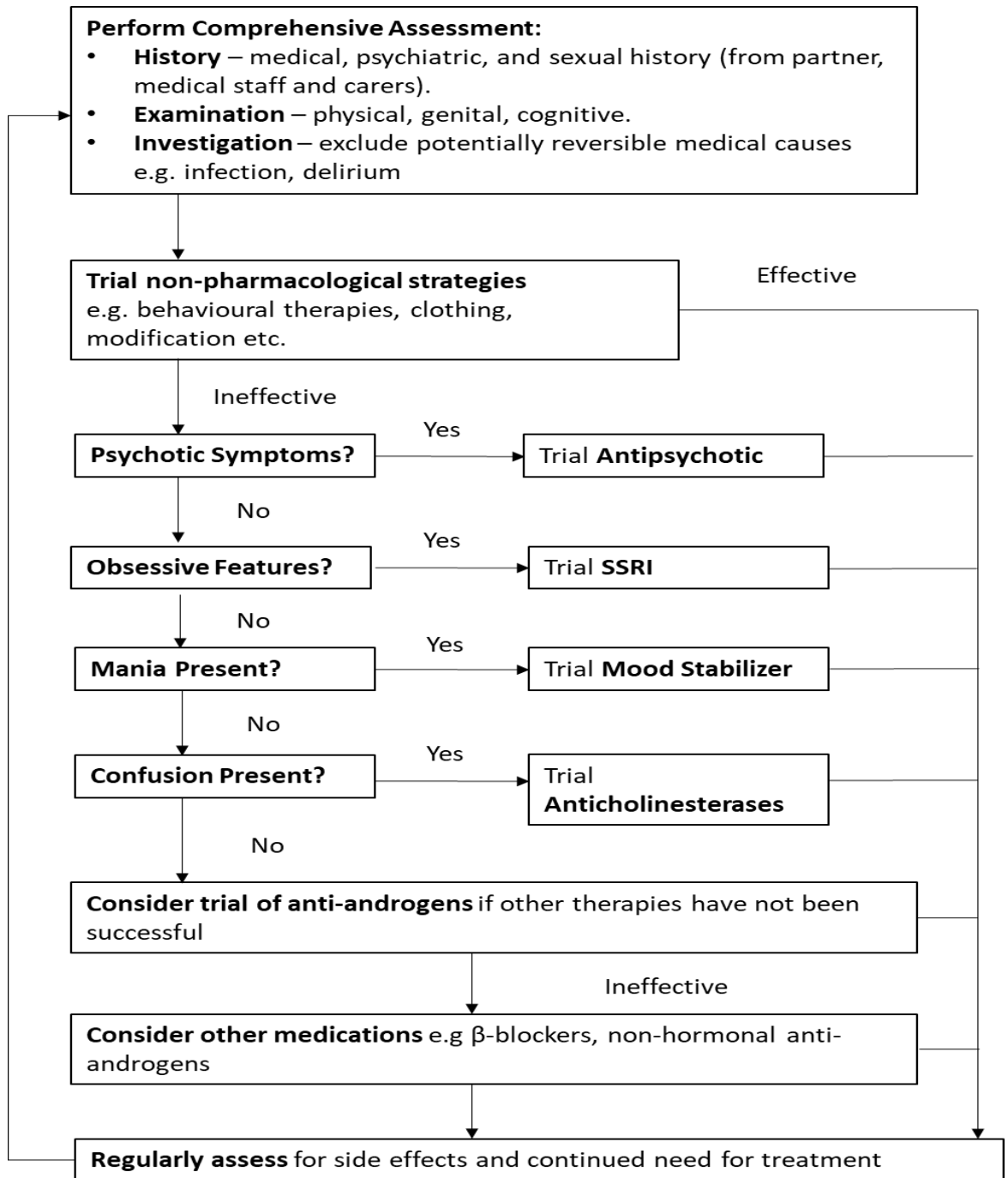
			unwanted fondling or kissing.	
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Bardell et al. (2011) conducted a retrospective study to explore 'inappropriate sexual behaviour' in older persons living with dementia. Ten people who were admitted to an inpatient geriatric psychiatry ward because of their 'sexual behaviours', were compared with ten persons who were admitted to the same ward but were not seen to express themselves sexually. The aim of this study was to discover if any interventions reduced 'inappropriate sexual behaviour'. This study found that pharmacological prescriptions were the most frequently documented interventions, with citalopram being the most common drug prescribed to 'treat' any sexual 'behaviours' (Bardell et al. 2011). Even though citalopram was well tolerated, the drug resulted in only a minimal reduction of the behaviour in three people. Antipsychotics such as risperidone and olanzapine, were also prescribed with the ambition to suppressing any sexual expressions from the participants (Bardell et al. 2011).

Many people living with dementia, who express themselves sexually, are on several antipsychotic medications at once (Tucker 2010). Tucker (2010) provides an optional approach and algorithm in order to 'manage' sexual behaviours in people living with dementia (*see figure 12*). The algorithm suggests that people living with dementia who express themselves sexually should be given a full medical assessment including a sexual history, and a social history and information regarding previous relations in order to 'put the problematic behaviour in context'.

Tucker (2010) suggest that alongside assessing the history of the person, cognitive and neuropsychological assessments should be completed on a regular basis. Alongside a medical and social assessment, Joller et al. (2013) suggests that there should be laboratory testing should occur; further suggesting that sexual expression is a result of an unnatural physiological state. Tucker (2010) argues that non-pharmacological strategies such as behavioural therapies, clothing modification etc. should be trialled first. Failing the non-pharmacological approaches, practitioners are advised to move onto pharmacological methods to find a 'solution' for 'inappropriate sexual behaviour'.

Figure 12: Sexual Behaviours Algorithm (Tucker 2010)



There has been some research that has explored how healthcare professionals address and respond non-pharmacologically to sexual expression in persons living with dementia in healthcare settings (Bauer and Geront 2000; Nielson et al. 2017; Hayward et al. 2012). Addressing sexual expression with humour has been an occurring theme throughout the literature. Bauer and Geront (2000) conducted a phenomenological study investigating the nursing home carers' experiences of residents and their sexuality. Findings from this study found that joking and teasing with residents was an acknowledged way for staff to deal with sexuality in a nursing home (Bauer and Geront 2000). Whilst humour can be used in a therapeutic way to establish and maintain rapport, as well as to deal with incidents that are uncomfortable, joking is also known as to be an effective way to manipulate and control people. Teasing can be used as an effective strategy to discourage certain types of behaviour (Bauer and Geront 2000; Tzeng et al. 2009). Humour is a way nurses and carers have learned to avoid the ensuing of discomfort and embarrassment (Bauer and Geront 2000). Tzeng et al. (2000) also found that humour was a common way to deal with sexual expression in persons living with dementia in residential homes. The use of humour by carers regarding residents' sexuality mostly acts as a smokescreen which effectively conceals resident genuine needs and desires for sexual fulfilment. Joking hides the true face of residents' sexuality and conveys to residents the message that their sexual needs are not to be taken seriously (Bauer and Geront 2000). The humorous response to sexuality, which is so common, at best, serves to conceal the true nature of residents' sexual needs and desires. At worst, it not only denigrates residents as feeling and thinking individuals, but it perpetuates the many, already prevalent, sexual myths about older persons.

In addition to humour, Tzeng found that avoiding and ignoring sexual expression were also common responses by nursing staff. Similarly, the participants in Wiskerke and Manthrope's (2016) study also discussed how sexual expressions were ignored or persons were redirected to a place where they could have complete privacy (Wiskerke and Manthrope 2016). If any expression of sexual needs

and/or desires took place in public or communal areas, the resident was redirected from the place they were in. Distraction methods were also reported to have been effective in managing sexual behaviours within the care home setting (Tzeng et al. 2009; Wiskerke and Manthrope 2016). Distraction methods included encouraging persons in care home activities, watching television and talking about different subjects and were a useful way of avoiding addressing sexual expression in persons living with dementia (Wiskerke and Manthrope 2016).

Villar et al. (2018) explored staff responses and common practices towards partnered sexual expressions and relationships in long-term care facilities where at least one person is living with dementia. Nursing staff (n=2295) across 152 Spanish long-term care facilities were recruited and responded to a questionnaire survey. Discussing sexual expression with a colleague or supervisor was the most frequent chosen reaction in the survey. Participants seen sexual expression and intimate relationships involving persons with dementia as problematic and 70% felt taking any decision making into a group process was a sensible way to proceed. However, this may indicate that staff feel unequipped to respond to sexual expressions and relationships within the workplace. On a wider scale, and as other literature suggest, staff may feel uneducated and unsupported in discussing sexual expression in older persons, both living with and without dementia within nursing and care home settings. After discussing with colleagues and supervisors, the second most frequently chosen alternatives are the ones that restrict sexual relationships involving persons living with dementia, that is, either taking direct measures to prevent situations from happening or 'telling-off' the residents (Villar et al. 2018). Overall, when responding to expressions of a sexual nature, around 40% of participants agreed that restriction was a common practice intervention in the long-term care facility (Villar et al. 2018). These results highlight the extent to which sexual relationships involving persons with dementia are seen as a problem for staff – a problem that many try to suppress, with all the detrimental implications for residents' sexual rights that this decision may have. In addition, fewer than one out of five participants chose an active supportive practice, trying to know more about

the situation or advising the residents involved how to minimise risks and/or to express their sexual needs properly (Villar et al. 2018).

Discussion

This literature review has aimed to evaluate the literature and evidence surrounding sexual expression in persons living with dementia. Understandings of sexual expression in persons living with dementia generally are rudimentary and often situated in behaviouristic and medicalised orientations, where sexual expression is viewed as problematic, unnatural and is thought of as a symptom of the dementia itself (Bauer et al. 2013; Hayward et al. 2012). Persons living with dementia have to face ageing and cognitive impairment stereotypes when it comes to sexuality and intimate relationships. This can be problematic given the value placed on attributes such as ability such as memorising, forming judgments and using problem-solving skills, all of which are characteristics that can decline with a dementia (Noguier et al. 2017). Thus, decline in cognitive ability can often result in diminution of value and greater dependency for fulfilment of day-to-day activities.

The need and wish to continue intimate relationships and to express one's sexuality also applies to persons living in nursing and care homes. It has been observed that older residents still see themselves as sexual beings with a continuous need and desire to express sexual desire (Bauer et al, 2013) whether that be physical intimacy, companionship, sex or how one is represented, irrespective of whether they lived in a residential care facility or not (Bauer et al, 2013). There was a widespread view that people living in residential facilities still thought about sex, and moreover, it was recognised that this was perfectly 'normal'. Even when residents may not have been interested in sexual intercourse, it was clear that other expressions of sexuality were very important to them (Bauer et al. 2013; Simpson et al. 2018). The only study to explore sexuality in nursing homes, which included a percentage of participants were persons living with mild dementia, was conducted in Australia (Bauer et al. 2013).

The interventions used by nurses in long-term care environments, namely facilitating privacy, using avoidance or distraction techniques have shown to be a short-term fix when responding to sexual expressions. Healthcare professionals have rated what they and/or researchers call apparent inappropriate sexual behaviours as the most difficult symptom of BPSD to manage and support (Tucker 2010). This is a major concern for nurses from the review findings. Challenges to responding to sexual expression include lack of privacy, negative staff attitudes, lack of education and balancing autonomy with protection from harm (Syme et al. 2017). At present, expressions of sexuality are regarded by many as nurses as inappropriate at best. At worst, they are regarded as 'abnormal', 'challenging' and behaviours to be managed with a view if possible, to stopping them or if not a least minimising them. These positions can be detrimental to older persons who are living with dementia and especially in terms of their sexual intimacy needs and desires. To improve the life and overall well-being of people with dementia living in nursing homes, there needs to be a person-centred approach to sexual expression rather than 'manage' a wide range of expressions. Most importantly, research regarding person with dementia and sexuality rarely includes the person with dementia themselves. The only way to get a real insight into the lives of people with dementia is to give them a 'voice': enabling them to speak of their individual needs combined with active listening.

Taking the findings from this review and considering them within a person-centred lens, there is some room for improvement before nurses providing care can be said to be person-centred, when considering sexual expression. The way in which nurses understand sexual expression seems incomplete and positioned in both behaviouristic and problematic orientations. Further, most research tends to focus on specific aspects of sexuality as sexual activity, rather than on broader and more diffuse view of sexual expression. The Person-centred Practice Framework explains that in order to provide effective person-centred care nurses should work with patient's beliefs and values and provide holistic care (McCormack and McCance

2017). This includes respecting the presence and value of sexual expression amongst individuals living with dementia.

In addition, by beginning to understand possible reasons as to why persons living with dementia might sexually express themselves in more direct or different ways, we can start to provide person-centred care. For example, it seems necessary to reiterate that nurses make assumptions about intimate contact, a form of sexual expression, without being sensitive to potential meanings and understandings by someone with dementia. Looking at the person as a whole being, including the sexual expression, through a person-centred lens we can begin to understand the reasons for sexual expression. Most research methodologies have been embedded in the positivist paradigm and there is a gap in the literature for both persons living with dementia, and nurses, to share their subjective experiences of sexual expression in nursing homes. It is not infeasible to argue that nurses and other carers are unfamiliar with these issues and this argument is supported by the literature review presented here.

Conclusion

This chapter offers an overview of the existing literature around sexual expression in persons living with dementia, and how sexual expression influences nursing care giving. This review demonstrates that the way in which nurses understand sexual expression seems incomplete and positioned in both behaviouristic and problematic orientations. Research does not explore sexual expression in persons in a holistic sense, rather research tends to focus on sexual activity only. Sexual expression needs to be researched within a worldview that views emotions, senses and desires as essential for developing meaning and how we express ourselves. Furthermore, the inclusion persons living with dementia, including persons who may be an 'adult with incapacity', within research concerning sexual expression needs to be more evident. To address these gaps in the literature, research methodologies need to be guided by person-centred and participatory principles, to be more inclusive of persons living with dementia. This leads me on to my next chapter, where I describe the methodology for this research.

Chapter Six: A Sensuous Methodology

Introduction

This chapter will concentrate on the methodological principles for this research. I am going to introduce a methodology I specifically developed for this research: a sensuous methodology. This methodology is built upon my philosophical foundations and blends different concepts and perspectives together to create a methodology that works for me and for this research. To help visualise my thinking and methodology, I call each part of the methodology a 'strand'. This chapter will show how the combining and intertwining of the three strands, from different theories and perspectives, has influenced my development of this sensuous methodology. The three strands are principles from: (1) existential phenomenology; (2) person-centred theory; and (3) sensuousness literature.

The decision of what methodology to use for a particular study is generally based on the philosophical stance that is underpinning the research and the questions that need to be answered (Costley et al. 2010). However, I am clear that this a methodology is not merely a formula or a recipe for me to select what research methods I was going to use. Rather, a methodology is a set of principles that stem from my own worldview, which then leads me on to a plan that broadly sets out how to go about acquiring the knowledge I needed to answer the research questions (Costley et al. 2010). I aim to demonstrate how the development of this methodology was not only interesting and creative but was necessary for this research. Since I have developed a new theoretical framework for this research, it was almost inevitable that a new methodology would emerge. Reaching this point has taken a lot of twists and turns in relation to not only how this research has progressed, but also how my perspective and thinking has evolved in this journey. Therefore, it is fitting to start this chapter with a personal reflection on how this journey has influenced the creation of a sensuous methodology and what the challenges have been during this process. I will then discuss each *strand* individually

before arguing how each strand can harmonise and complement one another to guide me further in this research.

Reflection

When I was exploring my philosophical position, I could see I was starting to walk along a phenomenological pathway for this research. There are many different interpretations of phenomenology as a methodology and the choice is dependent on how the researcher views phenomenology philosophically. As I paid close attention to perception, emotions and gaining meaning from the body, I situated myself within existential phenomenology as it has given emotion a central place in human existence (Thomas 2005). This very much correlated with my beliefs and I felt I was walking along the right path and that it would lead me to discover my methodology principles, what methods I would adopt for my research and how I interpreted the 'data' I would end up collecting.

As time moved on, my work progressed and my tentative theoretical framework had taken a new and exciting twist, I realised I was continuing along a taken for granted pathway in terms of my methodology. When I sat down and began to creatively consider my methodology, I appreciated that something was missing with the methodology. I felt it just was not quite enough to focus on a 'traditional' existential phenomenology alone. I had added a new dynamic to my philosophical foundations of my research, so I felt that to have a coherent methodology, it too needed a new dynamic added to it. The methodology that I proposed at the start of my PhD, suddenly fell slightly out of synchronicity with my theoretical framework and my work on sensuousness. As the philosophical foundations are the significant infrastructures that shape this research, I needed a methodology that was in complete harmony with my framework. The path that I was on in the beginning, was now not the path for me to continue, but I could see no existing pathway available for me to take.

I was standing at a crossroads with various methodological avenues I could take. Traditionally, when crossroads are used as a metaphor to describe what decision to

make or what pathway to walk down, there is usually a 'correct' option or a right way to walk. Usually, it gives you the image that someone needs to make a choice between the 'good' or the 'bad' option. However, this crossroads was different to any decision I had to make before. Each pathway was an option I felt that I could take any and it would have given me some connections with my theoretical underpinnings, and I have no doubt, give me sound methodological principles for my research. I felt that each pathway in which I was seeing in front of me was a 'safe' option to progress my research. The options facing me had a phenomenological framework and had been demonstrated in previous research, which felt good for me. I knew that any of these pathways would lead me to have a comprehensive methodology that would guide me to my research methods and help me with my data collection and analysis. Nevertheless, I could find no existing methodology that was 'just right'. Therefore, I thought to myself that I could incorporate different elements and create my own path to walk down. This meant I could not rely on being 'safe' with my methodology. I needed to create my own way, similarly to how I created the Sensuous Framework. I began to see that I could blend different strands together to create my methodological principles.

I could feel that my thoughts and ideas around sensuousness were becoming more grounded and this needed to be felt within my methodology. This idea of blending different strands together was so interesting and could open so many possibilities for my research, but I knew I was going to be faced with challenges during this process. The process of blending different strands did not feel safe because there was a risk that this would not be successful, and this filled me with uncertainty. However, creating a methodology that is built from my philosophical tenants gave me encouragement. I kept referring to my previous chapters whilst developing this methodology to ensure my methodological principles were aligned with my ontological and epistemological principles. According to Dewar et al. (2017) necessary elements within person-centred research is being courageous and risk taking. Additionally, McCormack et al. (2017) claims that working in a person-centred way, whether that is in practice, education or research requires personal

bravery. If I were to take the 'safe' option for my methodology, I would not be living as the person-centred person I am. This also gave me reassurance that taking a risk with my methodology would be a worthwhile step for my research.

Throughout my thesis so far, I have voiced the need for a change when it comes to how we perceive and care for persons living with dementia who express their personal emotions and feelings, whether they are feelings of a sexual nature or otherwise. To reiterate, within this research there needs to be a framework that recognises that we are sensuous beings and our senses, emotions and desires are fundamental in understanding our world around us. In order to explore humans as sensuous beings, we need a methodology that allows us to explore sensuousness. This required me to take a leap of courage and create a pathway that would be unfamiliar and unexplored territory but could lead me to an exciting discovery.

In summary, up to this point, I have shared with you my reflection on how my scholarship so far has given me encouragement to construct a methodology that is coherent and consistent with my philosophical principles. I hope that I have conveyed that this process while both interesting and exciting was also essential if I wanted a methodology that was true to my values and beliefs. I mentioned in the introduction that I would draw on three strands and bring them together to create my methodology. In the following sections, I am now going to discuss each strand in more depth. However, the components of this proposed methodology should not be viewed as linear. Rather, each strand should be viewed as intertwined and overlapping with one another. The three strands should come together as one, but for the purpose of this chapter I am going to discuss each strand individually so it can be understood how my methodological principles have been constructed. It is also crucial for me to emphasise that there is no order of importance for each strand, they all shine, but complement one another to establish a coherent methodology. The idea that the strands should be viewed as intertwining are key for this chapter.

The Existential Phenomenology Strand

Within this strand, I am going to focus on how embodiment, including experiencing emotions, senses and desires, the four existentials (relationality, corporeality, spatiality and temporality) and radical reflection have an important contribution within this methodology.

Embodiment

To recap, in my theoretical framework, I have discussed the importance of the body, emotions, senses and desires, and my exploration of what it means to be a person within this world, and this will feature strongly within my methodological principles. From my perspective, the body carries forward the meaning of a situation. As a result of our embodied understandings, we learn to go on with our thinking, how to carry a situation in a fulfilling way. To reiterate from my philosophical chapter, Merleau-Ponty (1964) suggests that the subjective view of the body is primary; one must have experience of the world before one can start developing knowledge of the world and generate meaning. Therefore, our bodily point of view is the ordinary intuitive understanding we have of ourselves as embodied perceivers (Carman 2008). The body is integral to any understanding of an experience or situation, therefore paying close attention to the body is a crucial component of this research and should be featured strongly within my methodology principles. The body is the barest raw material of a genuine presence in the world that provides the possibility of presence in the world (Merleau-Ponty 1962). It serves as a starting point of 'truth' and 'knowing' because one cannot separate from one's bodily situation or disengage from the world in which one exists. The body is critical to lived experience, because it is the means in which one approaches, senses, and absorbs the world.

Valuing emotions, sense and desires will be a core principle for this research. I will pay close attention to embodied ways of knowing and how we gain knowledge from our feelings, sensations and pleasures. Emotions are crucial for gaining meaning in our experience and have a key role in this methodology. Johnson (1999) discusses

the importance of embodiment and our emotions in making sense of our world. For this immanent or embodied meaning, Johnson (1999) argues that we must look more deeply into aspects of experience that lie beneath words and sentences. He argues that we must look at the felt qualities, images, feelings, and emotions that ground our more abstracts of meanings. Therefore, emotions are integral to our ability to grasp the meaning of a situation and to act appropriately in response to it. Emotions are viewed as a central part of life and of being-in-the-world within existential phenomenology, unlike other philosophies and methodologies that often view emotions as inferior to reason (Thomas 2005). Throughout this research process, I will pay close attention to how participants are expressing themselves through their body and enquire about how certain experiences made the participant feel at bodily level. In addition, I will also be aware of my body through reflexivity.

The Four Existentials as a Guide for Discovering Human Experience

One way to assist in a reflective inquiry process is to employ the existentials of lived relation (relationality), lived body (corporeality), lived space (spatiality) and lived time (temporality) to explore phenomena in a heuristic manner. The notions of lived relation, body, space and time are existentials in the sense that they belong to everyone's life world – they are universal themes of life. For example, in *Phenomenology of Perception* (1962), Merleau-Ponty's has major sections on body, spatiality, others or relations, and temporality. These fundamental existentials occur repeatedly in the phenomenological literature. We all experience our world and reality through these existentials. The four fundamentals may be seen to belong to the existential ground by way of which all human beings experience the world, although not all in the same modality of course. In the phenomenological literature these four categories have been considered as belonging to the fundamental structure of the lifeworld (Merleau-Ponty 1962).

Van Manen (2014) suggests life-world existentials of lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality) can be used as guides to reflection during data analysis. As these four existentials

belong to the fundamental structure of the life-world, I consider them as integral to the methodology including data analysis for this research. In this research and methodology I will draw on Merleau-Ponty's four existentials as it will ensure greater philosophical consistency and situate the analysis within lived primordial or pre-reflexive experience, and overtly focus on and value the lived experience of persons with dementia.

Before sitting down to write this chapter, I was struggling on how to connect the philosophical ideas of the four existentials and how it relates into practical research. Reading van Manen's ideas in his *Phenomenology of Practice* (2014) helped me with this process as he demonstrates how Merleau-Ponty's work on the four existentials influences his pedagogical research. This encouraged me to mull over and 'play with' the following question:

How can the existentials of body, relation, space and time assist and guide me in exploring the meaning and the lived experience of sexual expression in persons living with dementia?

The four existentials are always intrinsically connected with one another and can never be separated (Merleau-Ponty 1962). Rather than separating the existentials apart, I 'focused into' each of the existentials in turn but kept perspective that they are always related, so I can make stronger connection between the philosophical ideas and my methods for this research. This helped me see how the individual existentials come together to create a greater understanding of a person's lifeworld.

Relationality – Lived Self-Other

Lived other (relationality) is the lived relation we maintain with others in the interpersonal space that we share with them. As we meet the other, we approach the other in a corporeal way, we are able to develop a conversational relation which allows us to transcend ourselves (van Manen 2014). The existential theme of relationality may guide our reflection to ask how self and others are experienced with respect to the phenomenon that is being studied. To explore relational aspects

of a phenomenon is to explore how people are connected. For example: In what way is the subject-object relation constituted? Specifically, for my research and when participating in observations, interviews and analysis, I may ask myself the following questions: what is the relation between the person living with dementia and the nurse providing their care? How is this relation affecting the other? Is this relation enabling the other to flourish as a person, or is the other getting treated as an object? By asking these questions, I can discover how the relationship between persons living with dementia and the nurses providing care is affecting the lived experience of sexual expression in persons living with dementia and how this relation affects nursing care practices.

Corporeality – Lived Body

The existential theme of corporeality may guide our reflection to ask how the body is experienced with respect to the phenomenon that is being studied. Lived body (corporeality) refers to the phenomenological position that we are always bodily in the world. In our physical or bodily presence, we both reveal something about ourselves and we always conceal something at the same time – not necessarily conscious or deliberately, but rather in spite of ourselves. For instance, when the body is the object of someone else's gaze, it may lose its naturalness or instead it may happen that it grows enhanced in its modality of being (Sartre 1956). Under the critical gaze the body may turn awkward, nervous and the motions may appear clumsy, while under the admiring gaze the body surpasses its usual grace and its normal abilities. Similarly, the person in love may incarnate his or her erotic mode of being in a subtle glow or radiant face or sometimes under the eyes of the beloved, in a blushing response (Sartre 1956).

As I want to explore the phenomena of sexual expression, which is expressed through the body, corporeality will be an important existential to reflect on. I aim to explore how our emotions, desires and sensations are expressed through the body. Questions I may reflect on for my research are: What are persons living with dementia perceiving and feeling in relation to how they express themselves? How do nurses perceive and experience bodily expressions in person living with

dementia? How and when do we become aware of our bodies and when do others become aware of our bodies? What bodily expressions get perceived as stemming from a sexual desire? How do bodily expressions compare when a person is clothed compared to being in the flesh?

Spatiality – Lived Space

The existential theme of spatiality may guide our reflection to ask how space is experienced with respect to the phenomenon that is being studied. To understand a phenomenon, it is helpful to inquire into the nature of the lived space that renders that particular experience its quality of meaning (van Manen 2014). Lived space is a category for inquiring into the ways we experience the affairs of our day to day existence; in addition, it helps us uncover more fundamental meaning dimensions of lived life (van Manen 2014). Lived space is felt space. According to van Manen (2014), lived space can be difficult to put into words since the experience of lived space (as lived time, body) is largely pre-verbal; we do not ordinarily reflect on it, and yet we know that space in which we find ourselves affects the way we feel. For example, we may feel more comfortable and 'at home' in certain spaces than others.

In relation to my research, moving into a nursing home can be a daunting and unusual space to be in. Therefore, questions I may reflect on are: how does being in a nursing home setting shape our emotions and feelings? How is the space in a private room experienced differently from the communal areas of the nursing home? Do the various spaces within a nursing home effect the relationship between the person with dementia and the nurse? How are expressions of sexual expression perceived within different spaces within the nursing home?

Temporality – Lived Time

The existential theme of temporality may guide our reflection to ask how time is experienced with respect to the phenomenon that is being studied. Lived time (temporality) is subjective time as opposed to clock time or objective time (van Manen 2014). Lived time is the time that appears to speed up when we enjoy

ourselves, or slow down when we feel bored or anxious. Lived time is also our temporal way of being in the world – as an older person recollecting the past, or a young person oriented to an open and beckoning future. We experience the time of waiting differently from when we are involved in something. According to van Manen (2014), lived time and space are mingled. Space is an aspect of time, and time is experienced as space. That is why we speak of the ‘length’ of time it takes to do something (van Manen 2014). Our sense of identity is experienced in terms of times of our childhood, the periods of our working or love life, and so forth. The temporal dimensions of past, present, and future constitute the horizons of a person’s temporal landscape.

Therefore, for this research I will be reflecting on the temporal aspects of a person when exploring the phenomena of sexual expression in persons living with dementia as their expressions could be a result of how their past has influenced them and/or what their hopes are for the future. When working with nurses, I will be inquiring and reflecting on the temporal aspects of how they perceive and respond to expressions of sexual expression. For example, what personal and/or professional experiences has influenced the way the care for persons living with dementia and responds to sexual expression?

The four existentials of lived body, lived space, lived time, and lived relation to the other that I am using in my research can be differentiated, but not separated. They all form an instigate unity which we call the lifeworld – our lived world. However, in a research study we can momentarily study the existentials in their differentiated aspects, while realising that one existential always calls forth the other aspects (van Manen 2014). Using the four existentials of corporeality, relationality, spatiality and temporality will assist and guide me in exploring the meaning and the lived experience of sexual expression in persons living with dementia.

Radical Reflection

A key principle of human research, and of this research, is the belief that researchers should be reflective and reflexive. All phenomenologists tend to accept

that researcher subjectivity is inevitably implicated in research and some would say it is the realisation of the intersubjective interconnectedness between researcher and participants that characterises phenomenology (Finlay 2009). One particularly divisive issue for phenomenologist is how much attention they should pay to bringing their own experience to the foreground and reflexively exploring and realising their own embodied subjectivity. Some researchers believe in the importance of reduction as a process to ensure the researcher is non-influential and neutral as possible. For this process, researchers attempt to 'bracket' their previous understandings, past knowledge, and assumptions about the phenomenon so they can focus on the phenomenon only as it is appearing to them in that particular research (Finlay 2009). However, Merleau-Ponty (1962) argues:

'The most important lesson which the reduction teaches us is the impossibility of a complete reduction'

(Phenomenology of Perception, xiv/xv).

In other words, from Merleau-Ponty's perspective, complete reduction or bracketing is impossible to achieve. Finlay (2009) claims that with phenomenological reduction or the bracketing of the natural attitude, does not reveal anything sensational. With regards to this issue around 'bracketing', my belief is that it is impossible for a researcher to stand outside the lifeworld and observe it from a distance, which appeared to be required with bracketing. It seemed to me that the fact that a researcher takes up a project in the first place indicates they are already deeply immersed in the topic. I am inseparable from this study and I am carrying myself throughout this whole journey. In this research I have aimed to engage in honest self-aware reflectivity and reflection from the start, with focussing on my beliefs and values around personhood and this has continued throughout the thesis. Therefore, I am unable to 'bracket' and remove myself away from my research during data collection, engaging and connecting with participants, and the analysis. Instead, I am going to engage in radical reflection, and this will be a key feature in this methodology.

Merleau-Ponty argues that radical reflection is relearning to look at the world is thus far from being a one-off event of learning, performed once and forever (Merleau-Ponty 1962; Finlay 2009). It is an act of learning which takes an entire lifetime, which takes place every moment we perceive. Therefore, rather than attempt to disconnect from my values and assumptions, I will expose them through radical reflection. Radical reflection supports deep and meaningful reflection, where I make my experience and assumptions explicit. This process where I acknowledge my perceptions and experiences, puts me in a better position to have a fuller understanding of the perceptions and experiences of those to the participants. Radical reflection grasps the unreflective, but it does so only by perceiving it, which already means, to a certain extent, constituting, inventing and creating it.

According to Merleau-Ponty, existential phenomenology, is a philosophy that sees people in a world that already exists before any reflection. Merleau-Ponty's phenomenology is existentialist in the sense that it deals with the existence people are in a pre-given world. His work aimed to encourage interpretation and dialogue to bring awareness of experience and the meaning of the experience (Thomas and Pollio 2002). In the *Visible and Invisible (1968)*, Merleau-Ponty begins to speak of our being-in-the-world or our natural attitude as characterised by a perceptual faith, prior to the questions of proof or knowledge introduced by scientific or philosophical reflection. He argues a person cannot reflect on lived experience while living through the experience. Thus, phenomenological reflection is not introspective, but retrospective. Phenomenology is the study of lived or existential meanings; it attempts to describe and interpret these meanings to a certain degree of depth and richness and attempts to explicate the meanings as we live in our everyday existence, our lifeworld (Merleau-Ponty 1968). The insight into the essence of a phenomenon involves a process of reflectively appropriating, of clarifying, and of making explicit the essence of the lived experience. Therefore, the meaning of lived experience is multi-dimensional and multi-layered (van Manen 2014). Reflecting on the lived experience then becomes reflectively analysing the essence or thematic aspects of that experience:

'When I begin to reflect, my reflection bears upon an unreflective experience; my reflection cannot be unaware of itself as an event, and so it appears to itself as a truly creative art, as a change in the structure of consciousness, and yet it has to recognize, beneath [en deçà] its own operations, the world which is given to the subject because the subject is given to itself. The real has to be described, not constructed or constituted.'

(Merleau-Ponty 1962 , x/xi).

Philosophically, radical reflection has a task of reminding perception of that which it tends to forget, namely its own accomplishments (Dorfman 2007). Perception omits that the objective world is not independent of it but constantly created by it. This is the reason why perception needs reflection, yet it is not a detached reflection, posterior to perception, but rather a perception aware of itself as an event or a creation (Dorfman 2007). It is a perception which does not let itself 'be carried away', overestimating its power and forgetting its origin in the external world, as does intellectualist reflection, nor forgetting its constitutive and creative power, as does empiricist reflection. In this manner phenomenology proposes a continual renewal of perception, an endless process of creation which at the same time recognises and modifies its origin. Therefore, to understand the phenomena being studied, I reflected on my own lived experiences to understand the phenomenon under study. I also continuously reflected on the process of the research and how my perceptions have changed after every interaction I have with the participants. This brought my pre-assumptions up to the surface so they can be felt and as fully recognised as possible. This process enabled the ability to differentiate my lived experiences and assumptions on the phenomena and that of the participants so that their voices and experience do not get lost amongst my own reflections. Engaging in radical reflection, also allowed me to comprehend the literature surrounding the phenomena of sexual expression, make sense of it, but then not permit my knowledge of the empirical literature to influence my interpretations of the participants lived experiences.

To summarise so far, it should be clear that theories and ideas of existential phenomenology will contribute to my methodological principles for this research. The reader should also see and feel that these principles strongly concur with my philosophical underpinnings and my connections with the embodiment philosophy of Merleau-Ponty and Johnson's work by concentrating on how emotions are crucial for gaining meaning in the world we live in. I have also discussed how the four existentials of relationality, corporeality, spatiality and temporality are in assisting a reflective analysis approach to this research. Following on from this I have argued my rationale for not going down a reduction, 'bracketing' route, and instead I am going to engage in a radical reflective process. In the following section I discuss my next *strand*; the person-centred and participatory components and how this influenced my methodology. Then I will discuss the major twist this methodology takes, which is my incorporation of a sensuousness element to this research methodology, which as far as I am aware, is an original contribution in nursing research.

Person-centred Principles

What is important for me, is that I live this research with person-centred values. I believe that I am person-centred not only in my nursing practice, but in my everyday life. Therefore, it is very valuable for me as a person to be a person-centred as a researcher and to continue and carry out this study that was underpinned by my person-centred values. The principles that I am going to talk about in this strand of my methodology are: privileging and engaging authentically with participants over detaching myself from the research, working with the person's beliefs and offering free choice, researching with persons and not on people. Strong participatory values within this research is something that I strived to achieve. Participants are just as much of a stakeholder in this research as I am and certainly, this PhD study would not have been possible if it were not for participants. Therefore, I initially considered having a participatory action research (PAR) approach or element to this research. However, after some consideration, I concluded that having a strong PAR component to this study, did not feel

appropriate. Although my research is going to involve participation, and possibly some element of action, PAR is about persons engaging in collaborative processes 'aimed at improving and understanding their worlds in or order to change them' (McIntyre 2008, p. ix). In this study, while I will be attempting to understand the lived experiences of persons with dementia and nurses, I am not setting out to intentionally change anything. The outcomes may include greater self-awareness and facilitate the opportunity for chance for individuals who participate in this study, but this change would be their personal intention of the research process. With this said, this research will have participatory values and there could be scope for future PAR on developing the work of sensuousness.

Engaging Authentically over Detachment

Existential phenomenologists view persons as embodied beings, where the reasoning and cognitive powers that they show are simply the visible part of a much deeper and wider engagement in the world (Han-Pile 2009), and it is through this practical engagement with the world that people develop knowledge (Cooper 2012). I aimed to make this an important principle when thinking about person-centred aspect of this research. So, I sought knowledge that is based on data obtained through participation (Matthews 2006). A proper investigation of life or existence requires methodologies that include practical engagement and connection, rather than distancing myself from the research and the participants. Deeper engagement brings you closer to others in the world and enhanced the possibly to appreciate others experiences more.

Knowledge originated in what exists in a person's consciousness and feelings as a result of the experiences and the projects they adopt during their life. An existential phenomenologist is unalterably opposed to the exploitation of others, so gaining access to and using that store of knowledge requires collaboration. Direct interaction between people enables each person involved to understand and 'feel' the other to a much greater extent than when we simply observe an interaction between others (Heron 1981). This awareness of the other person as a presence deepens 'when we are in a very aware, committed, concerned, exploratory,

inquiring relationship' (Heron 1981, p. 30). Likewise, as the validity of knowledge is determined by its value to the individual, collaboration is required to ensure that the outcomes have value for all people involved.

The art of the researcher in this person-centred research is to keep the question (of the meaning of the phenomenon) open, to keep themselves and the 'interviewee' orientated to the substance of the thing being questioned (van Manen 2016). The participant becomes the co-investigator of the study (van Manen 2016; McCormack et al. 2017). Both the researcher and the participant weigh the appropriateness of each 'theme' by asking: 'is this what the experience is really like?' And thus, interviews and participant observations indeed turn into an interpretative conversation where in both partners self-reflectively orient themselves to the interpersonal and collective ground that brings the significance of phenomenological question to view (van Manen 2016). Collaborative discussions and engagements are helpful in generating deeper insights and understandings. Therefore, research should engage with participants authentically and become immersed in the research as much as the participant, rather than stay on the periphery and be detached from the participant and the research process.

[Working with the Person's Beliefs and Offering Free Choice.](#)

Existential phenomenology and person-centred research focus on the unique individual person, and the freedom and responsibility that is tied up with their ability to make informed choice (Cooper 2012). Research must therefore be flexible enough to enable people to make different choices and to work with the choices that they make without trying to 'correct' them, coerce them or be judgmental. A choice that may be right for one person, may not be right for another, or the initial choice made by a person may be changed in the light of what is for them at that point in time.

Existential phenomenology as a philosophy is a doctrine that believes persons are autonomous beings, and as such they have the power and the will to make choices, and always striving to 'become', to develop and to flourish. This is also very

important in person-centred research. It is the possibility of having a choice that is both central to taking action and central to personal development. Research on people should therefore never attempt to provide a definitive answer as this would result in people being confined or constrained (Matthews 2006). Trust and consent lie at the heart of an ethical relationship in all research. There should be an emphasis on the intrinsic value of each person with dementia, rather than on their decision-making competence.

Researching with Persons and Not on Persons: Developing a Person-centred Relationship

Despite my aspirations for this research to be as participatory as possible, I needed to be aware that participants were not going to fulfil text book images of a co-researcher in this study, where they would ideally be involved as much as they wanted in every part of the research, including design. Although the persons with dementia and the nursing staff are going to be participants in this research as opposed to subject, this was not going to be a fully an ideal participatory study. Rather, this methodology would incorporate some participatory principles. Participatory research has been defining as an,

‘action-oriented research activity in which ordinary people address common needs arising in their daily lives and in the process generate knowledge’

(Park 2006, p83).

The key element of participatory research that made it unsuitable for this study was the central role that participants would have to play, potentially determining what problems to address and taking the lead or shared lead in the research process. As the researcher, I recognised that I undertook the initial design and planning of the study. However, decisions made once this study was underway took place in collaboration with participants, and some of the key features in the design of the research are there to make participation as easy as possible for research participants. While participants were involved in this research, no decision was made by me without the participant’s views and wishes being considered. I tried to

ensure that this research was conducted in a way that gave participants free choice and the ability to work with their values.

'Being person-centred' sets out expectations about the relationship between the researcher and the participants in the research (Skovdahl and Dewing 2017).

Person-centredness contains core concepts that sit within my underlying philosophy. Person-centredness emphasise the unique nature of everyone in the study (the participants and the researcher), individual backgrounds, values and beliefs that need to be considered, and within a context that will also influence individual participation and hence the whole study. Being person-centred is to strive towards human flourishing for all (McCormack and McCance 2017). Being person-centred should therefore be flexible, be done with people rather than on them, and should share the generation of knowledge. The interaction is most effective where the people feel safe, respected and valued, so the relationship between all the participants is a key part of the methodology. Relationships are perhaps the most visible feature of the enactment of person-centredness in any context (Skovdahl and Dewing 2017). Overall, the best interest of the participants (person living with dementia and nurses) would always take priority over research methods and data. To summarise, the three major person-centred principles which featured in my research are:

- Engaging authentically over detachment.
- Working with the person's values and beliefs and giving them free choice.
- Researching with people and not on people: developing a person-centred relationship.

[A Strand of Sensuousness](#)

The third and final strand that makes up my methodology is where the exciting twist comes into it. Together with existential phenomenological theory and person-centred principles, I want to blend in a strand of sensuousness. In Chapter Four, I spoke about how we need a new perspective to perceive and look at sexual expression. Thus, this needs to be visible within my methodology; further, I want to

pay attention to the sensibilities of the participants and myself as the researcher. By thoroughly searching phenomenological and research literature, I found no existing phenomenological methodology that explicitly included principles based on sensuousness and that acknowledged that persons are sensuous beings. At that point I returned to the philosophy.

Merleau-Ponty (1962, p.230) argues we must give a clear account of the nature of sensible significance, otherwise we shall merely slip back into the intellectualist analysis which Merleau-Ponty rejects. Sensibility is part of us all and I want this to be recognised and clearly visible in this methodology. Drawing upon Merleau-Ponty's ideas, Lingis (1993) claims that the body is a 'sensible essence' in that it connects us to our world through our sensations and feelings. Merleau-Ponty describes in his text, *The Visible and the Invisible*, that literature, music, art, and the passions as 'the exploration of an invisible and the disclosure of a universe of ideas', although in such cases these ideas 'cannot be detached from the sensible appearance...' (Merleau-Ponty 1968, p. 42). We are our bodies, and we experience emotions, senses, desires and pleasures as part of our embodiment. Therefore, to reiterate my position from the previous chapter, through human sensuousness we can have a greater understanding of our lived experiences.

I wanted to discover if there was anything published that focused on incorporating a 'sensuousness' element, with regards to research methodology, even out with the discipline of nursing and health. I came across van Ede's (2009) paper on 'Sensuous Anthropology', in which he calls for ethnographic researchers to bring in a sensuous element to an ethnographic methodology. Coming from a performing arts background, van Ede (2009) encourages researchers who use participatory observation, which many ethnographers use as their main method for data collection, to step outside the outlined methodologies of western science and 'ocularcentrism', which privileges vision over all the other senses. Van Ede (2009) suggests that all the senses together touch upon the essence of human perception, of the world and the self within that world, upon one's interpretation and creation of that world. I agree with van Ede that our senses are crucial in understanding

human sensibility and all senses should be considered in a sensuous methodology. However, the way I view sensuousness is much broader than incorporating the senses alone. To recap, my definition of sensuousness is as follows:

‘The gratification and/or expression of our emotions, senses and/or desires’

This definition of sensuous incorporates all sensations and emotions that we feel and how our body reacts to those sensations and emotions. Therefore, it can be clearly seen that the senses are an integral part in our human sensibility, however it is not just that. Humans are sensuous, embodied beings who experience emotions, senses and desires. Our emotions, senses and desires result in feelings, sensations and pleasures respectively. As emotions, senses and desires are embodied, it is through the body that feelings, sensations and pleasures are expressed. Within this research, I wanted my methodology to value and pay attention to human sensuousness. In my perspective, many methodological interpretations of phenomenology, places some value on the senses and/or emotions of the participants and the researcher. However, with the methodological principles I am describing, this methodology considered participant’s sensuous experience in much greater detail. For example, when interacting with participants during the research, I paid particular attention not just what events took place in the experiences, but attempted to capture the sensuous aspect of experiences and what emotions, senses and desires were most prominent in the experiences they described. I also continuously reflected on my senses and on my feelings throughout the research experience. I go on to explain this in more depth in the next chapter.

Conclusion

To summarise, I felt unable to walk down an existing pathway that had principles and methods already there presented for me to grasp. Therefore, I decided to blend different concepts to create a methodology that worked for me and for this research. It was always Merleau-Ponty’s (1962) views that we are, as it were, woven corporally both into the material world we perceive and onto the social world we inhabit; that we do not stand outside the world, peering in at it, but already inhabit

and incorporate from within. Just like the intertwining relationship between body and world, the methodological principles are all intertwined.

A researcher, when investigating a phenomenon starting from the experience lived by the participants, obtains their description of their experience and then has significant discourses that can be understood and to have their essence unveiled. Existential phenomenology is discovery orientated; it wants to find out what a certain phenomenon means and how it is experienced. I have merged certain person-centred principles with existential phenomenology, whilst bringing in a sensuous quality to the methodology. Through this methodology I entered as closely as possible, the lifeworld of participants to understand their lived experience. In other words, this methodology was guided by the following principles:

- The researcher – participant relationship is subjective, interactive and interdependent (person-centred).
- Participants will be included in the research as far as possible and will be offered free choice (person-centred).
- The four existentials (corporeality, relationality, spatiality and temporality) will be used as guides for discovery and reflecting on human experience (existential phenomenology).
- Embodiment will be highly valued, and the researcher will pay close attention to emotions, senses and desires throughout this research (existential phenomenology/sensuousness).
- Researcher is aware and explicit how own views (prejudices) can influence the research process and interpretations of text but will not attempt to bracket them. Rather the researcher will engage in radical reflection throughout in order to be to bring together the perspectives of others and self (person-centred/existential phenomenology).

- Researcher uses own knowledge, senses, emotions, intuitions and imagination to understand nuances embedded in the lived experiences (existential phenomenology/sensuousness).

Chapter Seven: Fulfilling my Methodological Principles

Introduction

Having described the development of a sensuous methodology and its key principles in the previous chapter, I now turn to the implementation of these principles and how it has driven the practical features of this research. Traditionally, 'research methods' is a term commonly used to describe the process and systematic steps one takes to exclusively 'collect data' or information. For me, research methods are not a fixed set of procedures or a 'recipe' that a researcher must follow to achieve the results they are aiming for. Rather, methods are opportunities to explore the phenomena under study to discover new knowledge and understanding (van Manen 2014). Therefore, I align myself with van Manen (2014), for whom, research methods need to be experienced holistically to allow the concrete, sensed, imaginative, aesthetic, embodied and relational nature of experience to be revealed.

In this chapter, I am going to begin by reiterating the research question and aims to refocus on what this research aspired to achieve. Following this, I will share the methods I used which enabled me to step into the research field and gather information and meaningful experiences from participants that took part in this research. I will also illustrate how I worked with the participant's transcripts and the field notes I took throughout the research to seek meaning and present them as findings. Each section of this chapter is guided mainly, but not exclusively, by one of the methodological principles, which I have stated at the beginning of the respective sections. I am organising my methods and findings into two different chapters, and I occasionally draw upon some examples from my field notes and transcripts to explain and provide examples within the chapter.

The research questions guiding this study are:

What is the meaning of sexual expression in persons living with dementia who live in a nursing home setting? And;

How is sexual expression experienced and understood by the nurses providing care?

The aims of this study are:

- To gain knowledge on meaning of sexual expression in persons living with dementia in a nursing home setting.
- To explore how sexual expression in persons living with dementia is understood by nurses working in the nursing home.
- To explore the relationship between sensuousness and sexual expression in person-centred nursing.

The objectives of this study are:

- To observe nurses at work and have conversational interviews with them to find out about their experiences of sexual expression by persons living with dementia.
- To find out from persons with dementia their experiences and views on sexual expression through conversational interviews.
- To explore this sensitive topic in a dignified and respectful way by working with a rigorous consent framework to include adults with incapacity (AWI).
- To gain insights into the nursing care of persons with dementia in the nursing home, useful for nurses in Scotland and beyond.

The Research Context

The initial approach to the nursing home where the research took place was made through an email to the care director. I had contacted several care directors from different nursing home companies in Scotland and I received a reply almost instantly from one care director saying they were interested in hosting my research study. The others replied saying they could not take on any extra projects at the time of me contacting them. Grateful to perfect timing the Care Director, who showed interest in the research, was attending an event that was being held at Queen Margaret University (QMU) two weeks after my initial approach. We decided

to have a meeting on the same day the care director was travelling to QMU. This provided me with the opportunity to connect with the director, elaborate the intricacies of the research and how I envisaged the study panning out as best to my knowledge. It also provided us with the opportunity to discuss the logistics of what is required for me to conduct the research at one of the nursing homes e.g. obtaining a disclosure and honorary contract.

Once I was granted full ethical approval from the QMU ethics committee (*Appendix 2*), the care director shared my research protocol with the nursing home manager of one of the group's homes. The manager and I were in a constant exchange of emails for several weeks before I was invited to visit the home and meet the manager along with some of the other staff. The manager felt that the staff would enjoy participating in the research and believed there were some residents who would meet the inclusion criteria and benefit from participating. This meeting occurred mid-December (2019) and we agreed that the research would officially start on the first full working week in January after the festive break, beginning with my induction to the home. In the meantime, in between Christmas and New Year, I visited the home to have further conversations with the manager and to meet more of the staff and persons living in the home. At this meeting I provided the home with a poster which they could display on their notice boards to raise awareness that a research project was occurring in the home. The poster included a summary of the study, a photograph of me as the researcher, and contact details should anyone require further information (*Appendix 3*).

The home had forty older persons living there, all with a diagnosis of dementia and was a place for persons who have been considered as needing extra support to address their care needs. The persons living in the home were often referred to as residents by the staff. I had numerous conversations with the persons living in the home about how they liked to be referred to when protecting their name and identity (e.g. an older person, resident or client) and each of them said they preferred the term, 'resident'. The home was called a 'nursing home' rather than a 'care home' as there are registered nurses in the home twenty-four hours a day. On

a typical day shift there would be a total of twelve nursing and care staff providing direct care to the residents. Of the twelve nursing and care staff, four would be registered nurses in keeping with nursing home safety standards (Legislation.gov.uk 2019). The following is a description of the nursing home which I wrote as part of my observation field notes on my first week (8th January 2020):

As I drove off the motorway, I saw signs informing me that I was only half a mile from my destination. I had just driven through one of the busiest cities in Scotland and now I am surrounded by scenic fields and driving alongside a small stream. The nursing home is on the outskirts of a small town in the West of Scotland. It sits in-between a national woodland area and a river, and the surroundings is very peaceful. You can hear the background traffic noise coming from the road bridge going across a wide river. The road noise is distant and certainly not overbearing.

The home is in a small and quiet cul-de-sac area, next to twenty assisted living cottages. Opposite the road to the home is a large state-of-the-art garden centre, with an in-house restaurant. You drive past the entrance on the right hand side of the road, and then a couple yards after, on your left, you have the entrance to the small housing estate which includes the nursing home and the cottages. Apart from the welcoming sign to the nursing home, and the size of the building, you could not distinguish the nursing home from the other cottages in the estate.

The nursing home is a modern new build. It is a light colour-ed building, with large glass doors and large windows. There is a small garden area in the front of the building which was divided into two parts due to the path that was created leading visitors from the car park to the front entrance. On each side of the path was a variety of plant pots embedded by garden pebbles. I walked up to the glass doors and I pressed the intercom buzzer to get connected to reception. Beside the entrance was a garden bench situated underneath a gold plaque, informing visitors of when the nursing home had its official opening and that it was opened by the Princess Royal.

At the front of the nursing home, I walked into a large and bright open space. Right away, I realised the large size of the home is very deceiving from the outside. To the right-hand side, was the conservatory area, which had a couple of three-seated light purple couches. This opened into a large area, which was often used for parties, concerts, exercise classes and sporting activities. The floor was wooden, a soft brown colour and the space was very light due to the glass doors, conservatory windows and two windows on the ceiling. The walls were filled decorated with photos of the residents at various events and numerous awards and achievements that the nursing home was proud of.

At the end of this large space was the reception desk, where all visitors would sign into the visitor's book which is placed on a white desk, next to a bowl filled with mints and sweeties for the visitors to help themselves. Just beyond the desk was the main corridor which leads to the four houses in the home. The staff were very particular about calling the four areas 'houses' and not 'units'. At the very beginning of the corridor was the manager's office and most of the time, her door would be open, so that she would say hello to anyone passing by.

The corridor was not as light as the open plan space as you walked in, but certainly not dark. The walls were painted lilac and a lot of photographs and art made the corridor interesting. Old photographs of Scotland were scattered across the walls, which many of the people living there would stop and reminisce regularly. One section of the corridor walls was filled with a wish tree, where residents would display their wish or ambition at the end of a branch and once that wish had been fulfilled, it was displayed on a blossomed leaf. Other areas of the corridor walls were covered by more photographs of fun events that were previously held in the home. There was also a notice board for both residents and visitors.

You could access any of the four houses in the home from the main corridor, as it ran through the middle of the home. The houses were interconnected as well and was laid out in a horse show shape, surrounding the main corridor. Each house consisted of ten, en-suit bedrooms, a large open plan, living-dining area, and garden. There were two kitchen areas in the home and each kitchen sat in between two houses. If both doors in the kitchen were open, you could be standing in the dining area of one house and able to see right through to the dining room to the house that was connected to the same kitchen.

Compared to the corridor and conservatory area, the houses were fitted with navy carpets rather than wooden floors. The only noise I could hear was the low volume of laughter coming from the presenters of 'This Morning' on the flat widescreen television. However, I was more drawn to the warming glow that came from the electronic fire that seemed to be the centrepiece of the lounge area. This gave the house a warm and homely feeling. There was two couches and five armchairs all focusing on the television and the fireplace. I could imagine wanting to get make this most of this area on a cold, dreich or even on a snowy winters' day, where I would sit and get cosy on the couch, holding a hot cup of tea or better still, a hot chocolate, watch a light-hearted classic movie and feel the warmth of the fire.

Next to the lounge was the dining area, which had four wooden tables, each table sitting up-to four people. Red placemats and coasters were on the tables, all ready for the next meal to be served. On a couple of the tables there was one or two forgotten cups of tea and coffee. A side plate covered

in toast crumbs was next to a mug of coffee. The smell of the coffee was filling the air, which gave me the impression that it was not long ago made.

In each of the houses lounge's there was also a nursing office, which you could only tell if a nurse was in there perhaps writing up her nursing notes. Otherwise the door would be closed, and it could easily have been mistaken for a cupboard or storage room. Every house has a separate lounge area, which had a unique theme. One of them is a football memories room, with so many framed football shirts hanging on the walls. Another was a sensory room, there was a reading room finally a beauty therapy room which a scent of aromatherapy candles filled the air.

It was a very frosty morning, so there was no one in the garden. The patio door out to the garden was never locked during the day, so anyone could go in and out as much as they pleased. The cream coloured curtains were pulled back letting a lot of sunlight into the lounge and dining area. Each garden area to the houses were a slightly different layout, but all were just as busy and colourful. There was a mixture of flowerpots, vegetable beds and rose bushes. This was the start of January so I could only imagine how vibrant the garden would be in the spring and summer. A light-coloured path circulated the entire home so that the residents living in the home could explore the different gardens around the home.

Each house mirrored this layout. There was a unique character within each house. Some houses were livelier, with laughter, noise, and chit-chat. Other houses had a more relaxed and calming atmosphere. This was influenced by the older persons living in the houses, but also by what staff were working in the houses. The staff were not assigned to a specific house, which I know is common practice in many nursing homes. For every house, there was generally one registered nurse and two carers caring for ten residents. The manager wanted to staff to know the entire home and therefore, would be assigned to work in a different house each day, and alongside different staff colleagues. The change in staff gave every house a different atmosphere each day, which made every day, to me, feel different and refreshing.

As part of the research, I worked in the nursing home as a registered nurse in an honorary capacity. Like Bland's (2002) ethnographic study in nursing homes, the honorary contract allowed me to partake in some care activities and immerse myself in the culture. However, I was supernumerary and I did not assist anyone with personal care, but took part in helping persons who needed assistance with meals, participated in fun activities and relaxation sessions, and could help with effective moving and handling (e.g. if a person needed a hoist to help them transfer

from wheelchair to couch etc.). I decided to get involved in this way as I could get to know the culture of the home and build relationships with the staff and residents, similar to the approach to research conducted by Saarnio et al. (2019) and Bland (2002). I attended the home two or three days a week, spending approximately 6-7 hours each day I was there. I was advised to dress smartly, usually wearing black trousers and a blouse/shirt, rather than a nurse's uniform so I would not be mistaken for a full-time registered nurse. The manager gave me a company name badge to wear during my fieldwork so that I was recognised as an honorary staff member of the nursing home company and was in the home as a researcher. I worked in the home for a total of three months. I planned to be there in total for approximately six months, however due to the implications of the COVID-19 pandemic, I was left with no option but to finish the fieldwork abruptly, which I discuss in more depth in Chapter Ten.

I spent a two-week introduction period to the nursing home, which consisted of an orientation to nursing care and building relationships with the staff and residents. The main purpose of this was to form relationships with not only potential participants, but all the staff and residents in the nursing home. Therefore, during the two-weeks, I started gently and only spoke of the research if someone asked me questions about the study. Once the introduction period was over, I began the recruitment and data collection phase of the research. This included handing out information sheets to nursing staff and giving the nursing team the opportunity to have private conversations with me about the study and to ask any questions. This also included the manager having conversations with family members of potential participants for recruiting persons with dementia, which will be explained in more detail later in the chapter.

All participants were informed that no information observed or shared to the researcher will be disclosed to other participants, nursing home staff, legal representatives, or family members. The only exception where a breach of confidentiality may have been required is if during any observation or discussion there was information disclosed that highlights issues of concern around risk to the

participant or others, or malpractice. As a health professional, I have a duty of care to raise issues of concern through appropriate channels in the organisation involved and adhere to the Nursing and Midwifery Council Code of Conduct (2018). If I saw any poor care or neglect, I agreed with the manager that I would report it to her. All participants, and the legal representatives of the persons living with dementia were informed that this would be the only time I could not keep confidentiality. During the research, I witnessed no unprofessional care, harm or neglect which I needed to escalate.

Introducing Participants

During my three months working in nursing home, I encountered four older persons living with dementia who chose to participate in the research. The names given for the purpose of anonymity in the research were, Frank, Steve, Ella and Archie. All four residents had a diagnosis of dementia, either Alzheimer's disease or vascular dementia. Each of them took part in conversational interviews with me. Two other potential participants agreed to take part in the research, but due to the COVID-19 pandemic, I could not visit the home and unfortunately had to end the research sooner than expected. I wrote to the persons whose participation in the research was cancelled, thanking them for their willingness to take part.

Eleven members of the nursing team volunteered to participate in the research. The eleven nursing team participants included seven care assistants, three registered nurses and the nursing home manager. I have called them, Valerie, Katie, Susan, Helen, David, Catherine, Emily, Liz, Tanya, Mark and Erin. I decided to group all the nursing and carer participants together under the 'nursing team' as I valued everyone's experiences of care and what they each brought to the team as individuals. I did not want to separate the registered nurses and the carers into separate participant groups and risk people possibly feeling undervalued (Coubrough 2008).

Inclusivity and Participation: Recruitment and Consent

Principle: 'Participants will be included in the research as far as possible and will be offered free choice.'

Kate Swaffer (2015), a dementia advocate who is living with dementia herself declared that there should be 'nothing about us, without us'. This quote reinforces the methodological principle that persons living with dementia have a right to be included in all research that is about them. Right from the beginning, when I was planning the research proposal it was my ambition to include persons living with dementia and be inclusive of adults with incapacity which is in keeping with international developments in dementia research (Alzheimer Europe 2011; Alzheimer's Disease International 2020). Persons living with dementia who met the following criteria were invited to take part in the study:

- Persons who have been diagnosed with dementia, or probable dementia.
- Persons who were happy to discuss their care experiences and experiences of sexual expressions.
- Persons who were over the age of 65.
- Persons who have been residing in the nursing home for more than one week.

From visiting and working in the home regularly throughout the data collection phase, I got the opportunity to get to know and form relationships with many of the residents. Much of my time spent in the nursing home was dedicated to establishing relationships with the residents. I discuss the process and significance of establishing relationships with the residents in more detail in the next section, but briefly it was being present and visible in the home and forming positive relationships that sparked curiosity about the research from the residents, especially Frank, Steve, Ella and Archie. They wondered who I was and what my purpose was for being in the home. After explaining to the residents that I was a nurse and a researcher exploring sexuality in older persons living with dementia, they voiced their own interest in the topic and dived straight into conversations

with me about their own sexual experience. Frank, Steve, Ella and Archie appeared to be fascinated around the topic and said they would be interested in participating in the research. Therefore, it was Frank, Steve, Ella and Archie voiced their own interest in this research that the recruitment process could begin.

I then spoke with the nursing home manager about these interactions with Frank, Steve, Ella and Archie to begin the recruitment process. Frank, Steve, Ella and Archie all had a medical diagnosis of dementia and were viewed by medical professionals and their representatives as not having the capacity to give informed consent. Therefore, the manager approached Frank, Steve, Ella and Archie's legal representative to ask permission if I could speak with them before approaching Frank, Steve, Ella and Archie. I had already been advised that it was sound ethical practice that the researcher should not approach a potential participant and their legal representative initially (Adults with Incapacity (Scotland) Act 2000). I was also aware of what I had set out in my formal ethics application, so I advised that the legal representative of the potential participant should be approached before the person with dementia themselves. When the legal representatives agreed to have a discussion with me, we sat down in the family room, which was a peaceful and private space in the home. I spoke to each family for approximately twenty to thirty minutes each where I explained the research and answered any questions they may have had. I also handed them the information sheet for legal representatives (*Appendix 4*).

I was pleasantly surprised about the response of the person's representative. My assumptions influenced my thoughts towards believing that the legal representative would need time to consider if they would like their relative to be part of this study. I imagined that they would ask many clarifying questions and want to be involved in the research process alongside with the person with dementia. On the contrary, the legal representatives of Frank, Steve, Ella and Archie, were more than happy for them to be approached to see if they would like to participate in the research, and they all signed the consent form for legal representatives (*Appendix 5*) when I initially spoke to them.

I had already met with Frank, Steve, Ella and Archie, had begun to get to know them as individuals, and discussed my research with them informally. However, it was not until I spoke with their legal representative and they gave consent for me to approach the person with dementia, that the nursing home manager approached the person with dementia formally about partaking in the research. Every person's representative received the opportunity to be at this initial discussion. However, each representative gave permission for their person to have the conversation with me and the manager on their own, unless they specifically requested their representative to be there. Frank, Steve, Ella and Archie opted to have this discussion on their own. It was made clear by the care home manager that agreeing to speak to me was not taken as giving consent to participate in the research to both the person with dementia and their representative. If the legal representatives agreed for their person to take part, and there was any sign that the person with dementia did not want to be included, then drawing on process consent and person-centred principles (Dewing 2008, 2017; McCormack and McCance 2017; Park 2006), the wishes of the person with dementia would be respected. The manager spoke to Frank, Steve, Ella and Archie in private and gave them a copy of the information sheet (*Appendix 6*), along with the summary version of the participant information sheet, which was amended to make it more legible for persons living with cognitive impairments (*Appendix 7*). Once they agreed to speak to me, I explained the research in more detail and Frank, Steve, Ella and Archie agreed to participate in the study.

The move towards person-centred care has resulted in growing acknowledgement that people with dementia have rights, including the rights for their experiences to be explored through research (McKeown et al. 2010; Higgins 2013; Flavin and Sinclair 2019). Traditionally, persons with dementia will not be included in research unless proxy consent has been given (McKeowan et al. 2010; Ries et al. 2017). In this research, in addition to gaining formal consent, methods associated with process consent were adopted to ensure person with dementia remains included throughout the research (Dewing 2008; 2017). This included recognising the wishes

of the person under their existing circumstances and incorporating inclusionary methods to ensure the person's involvement when seeking consent. The process consent method comprises five elements: background and preparation; establishing the basis for capacity; establishing the basis for capacity; initial consent; ongoing consent monitoring; and feedback and support (Dewing 2008; 2017). The method of process consent offers a pathway for researchers, but the process very much relies on the skills of the researcher in being able to engage with persons who have dementia and on their critical reflection skills. Through process consent, researchers come to know the participant and to tailor consents to their preferred means of communication (Thorogood et al. 2018). This is where I utilised the skills I had developed as a registered nurse working in clinical practice. Part of my role as a nursing home nurse was about knowing when someone with dementia is giving consent or not. Additionally, I attended educational sessions about the importance of critical reflection, a crucial aspect of being a person-centred researcher and research including persons living with dementia. Thus, I had engaged in critical reflection throughout my doctoral journey, and during my experience as a research assistant working on a practice development project.

During the discussion about participating in the research, I asked the person living with dementia about how they would feel about talking to me and sharing their experiences. At this point, and as part of the process consent method, I gathered information to understand how the person usually gives consent, and how they would normally communicate that they do not want to do something, or that something is causing them distress. This was recorded on the personalised research plan, which is described in more detail below, and formed the basis for ongoing consent. Throughout the research, consent was considered as an ongoing process to establish whether the person is happy to participate throughout each encounter (18th February 2020):

Ella: Thank you.

Karen: What for?

Ella: *Talking to me love, it's been ages since I have talked about this and you're a smart girl.*

Karen: *You're very welcome. Do you want to talk more or do you want to leave it there?*

Ella: *No keep talking love.*

It was important for me to understand how the person was feeling throughout the conversation and to get feedback as part of the process consent method. Again, I thought this would be something I would need to regularly check in with, but the person would often comment on how much they were enjoying discussing the topic of sexual expression and sharing their memories. It was reassuring and a pleasure to hear how much Frank, Steve, Ella and Archie appreciated taking part in the conversation. Below is an example from Steve's conversation where he gave me feedback about participating in the research (3rd February 2020):

Steve: *I had plenty of fun when I was younger and before I came in here. It's really nice to talk about it and remember, I never thought I would speak about this with someone again.*

Karen: *Do you like talking about this?*

Steve: *Oh aye, it's nice to talk about. You have made me smile today.*

Karen: *I'm glad you have enjoyed this.*

Steve: *I have, we should do this more.*

For the nursing team participants, I wanted them to feel that they could be included in the research as much or as little as they wanted too. Members of the nursing team who had experience of caring for persons living with dementia, were invited to take part in the research. The main concern here was that some participants would agree to take part without fully understanding what is being asked of them and/or feel compelled to take part. Therefore, I implemented several actions to minimise these feelings. An information sheet was provided to the entire nursing team in the nursing home (*Appendix 8*). The information sheet explained in more detail what the study involves, what is required by the individual if they would like to participate, and the associated risks and benefits. For anyone who was interested in taking part I provided sufficient time for the potential participants to read the

information sheet, think about whether they would like to take part and offer time and space to answer any clarifying questions or respond to any concerns. Everyone was informed that taking part was purely optional and they could have declined to take part in the study. The nursing team were informed that they could withdraw at any point during the research, as is their right, with no negative consequences for them. I set aside time for potential participants to have a conversation with me about partaking in the research and provided them with the opportunity to ask them any questions. Everyone was given the option to only participate in one aspect of the research, for example, someone may have wished to only engage in interviews and not observations or vice versa. Nevertheless, all the nursing team participants signed the consent form (*Appendix 9*) and agreed to participate in conversational interviews and observations of their care.

Developing Person-Centred Relationships

Principle: 'The researcher – participant relationship is subjective, interactive and interdependent.'

From exploring my values and beliefs at the beginning of my PhD journey, it was clear that I held the belief that all participants in research should feel valued and ensuring that all participants felt safe and respected throughout the research was crucial. I wanted there to be a trusting relationship between every participant and myself. I would want to achieve this in any relationship I encounter, whether that is with colleagues, friends, family, and persons that I care for. For the research, having an authentic relationship would encourage persons to talk about their experiences and to raise any concerns they may have had and make the research a meaningful process for all involved (Peters and Halcomb 2015). This was one of the main reasons I decided to work in the home and immerse myself into the culture, so that I could form relationships with participants. This section will explain what was involved in building up the relationships between myself and the participants.

For persons living with dementia, part of creating a trusting relationship was about getting to know the person. As well as getting familiar with the residents and staff

during my induction period, I wanted to have a fuller understanding and bond with the persons who wanted to be included in the research. I appreciated that discussing matters relating to sexual expression could be a sensitive topic to some persons living with dementia. Not only was it important for them to know the person, but it was also important for them to know me and feel safe and connected with me while I was speaking with them.

Establishing relationships with the residents living in the nursing home was an enjoyable and fulfilling process. However, even though the process of spending time with residents and forming a relationship was a meaningful experience and was essential for this research, it was time consuming and required a lot of energy from myself as the researcher. Establishing a trusting relationship did not happen overnight, or with one friendly conversation. As the researcher, I put in a lot of time and work into making myself known, and becoming a familiar face for the residents living in the home. Not only did I want to become a familiar face to all the older persons, I wanted to become a friendly one too. It was important for me to remember that I was a visitor in the older person's home and I was entering their living space. Therefore, I made an effort to say hello to everyone that was enjoying time in the lounge, dining room or garden. I would politely ask if I could be involved in the resident's daily routines, whether that was enjoying a cup of tea together, taking part in a fun game or activity, join them to watch television or have a walk around the building. This enabled the residents, whether they became participants in the research or not, to get to know me as a person and as time went by, I got to know the person and I could see they were becoming more comfortable with me and we were sharing more with one another.

I engaged in daily reflections to consider and evaluate how I was feeling being in the nursing home and how I felt the relationships with the older person were developing. After six weeks of visiting the home, and engaging with the residents, I noticed subtle but significant differences in how the residents were interacting with me from when I first arrived at the nursing home. For example, after a period of working on getting to know the residents, when I arrived in the home, I would be

greeted with smiles and waves from the residents and some would even take my hand and/or give me a friendly hug. I would regularly be invited by some residents to sit beside them to continue our previous conversation or partake in another fun activity with them. I noticed that some of the residents were asking me more personal questions about my life, whether that was about my family, social life or my personal hobbies. By sharing aspects about my life, the residents would find a connection with an aspect of their life and share with me a story that gave me a fuller sense of who they are as a person. Once I had started to see and this sense of connection occur regularly in my daily reflections, I became confident that the residents and I had established a trusting relationship, which was continuously evolving with every interaction.

I got the feeling that the residents enjoyed my company and by paying close attention to how they were interacting with me, and what they were sharing with me about themselves, I was confident that the relationship was a therapeutic and positive one for them. From actively listening to their stories, noticing their body language and receiving positive feedback from the residents, I was able to understand that by being present in the home and making an effort to engage meaningfully with them was bringing a positive experience to their day, which is an important principle for me in all relationships I encounter. Not only did this give me a positive indication that the residents were enjoying my company, this gave me a sense of belonging as a researcher. I was enjoying my visits more each day I spent in the home and felt I was learning a lot about the significance of connecting with persons prior to engaging with data collection.

It was during these moments of meaningful engagement and 'being-with' the residents, that Frank, Steve, Ella and Archie became interested in my research work. They wanted to know how I was progressing my nursing career, what my research project was exploring and what my main purpose was for being in the nursing home. As previously stated, I explained that I was interested to find out about sexual expression in persons living with dementia and their sexuality and/or sexual relationships have evolved since moving into a nursing home. This sparked an

interest in Frank, Steve, Ella and Archie. They asked me more questions about the research topic and started sharing some of their thoughts and experiences. I was able to see that this was a conversation that they were enjoying and the older persons living with dementia, expressed that they would like to have more conversations around sexuality and be part of the project I was undertaking. By putting a lot of time and effort into establishing trusting relationships, the residents that participated in the research felt comfortable to express their interests and presented themselves voluntarily for the research, before anyone approached them formally. Therefore, building relationships, opening a space for the residents to share an important part of their life and being present with them were crucial factors in the recruitment, data collection and analysis process of this research project.

Even though the persons living with dementia volunteered to be part of the research, ethically I had to follow appropriate research guidance and protocol. To ensure the safety and wellbeing of the person, there was also an ethical requirement to create a 'risk management' plan. The Department of Health (2007) requires risk management to be conducted in the spirit of collaboration and based on a trusting relationship between the 'service user and carers', or in this instance the participant and the researcher. Clarke et al. (2011) developed an empirically derived framework for assessing and managing risks for persons living with dementia, including adults with incapacity (AWI). I used this as a guide to ensure a thorough plan was in place prior to the person being included in the research. Through spending time with the person, and using the framework by Clarke et al. (2011) I was able to have a deeper understanding of the person and their values, in addition to how they respond to feeling upset or distressed. Therefore, I incorporated Clarke' et al. (2011) framework into a larger and more holistic approach in getting to know the person and creating a personalised research plan for the person living with dementia (*Appendix 10*). At the end of the research the research plan was given to the person and the manager for it to possibly be used later should they participate in future studies.

Understanding the life history of the person and how they currently live everyday life is important in understanding a person's psychological needs, safety needs, love and belonging needs, esteem and identity needs (Clarke et al. 2011). At this point, I had formal consent from both the person's representative and the person with dementia themselves, with the option for them to withdraw consent at any time. Nevertheless, I spent informal time with each person living with dementia who agreed to participate in the study. This ranged from simply having conversations over a cup of tea, spending time in the garden, playing a game of dominoes or cards. I did not use these interactions as opportunities to gather data and use it for the analysis. I got to find out about the person's life history, their likes and dislikes, and some of the important needs that is significant to that person. Taking time getting to know the participant before engaging in data collection is a regular feature in qualitative studies (Mckeown et al. 2010; Moore et al. 2003; Dempsey et al. 2016). Spending some time with the person prior to them participating in data collection, helped establish a trusting relationship between the person living with dementia and myself. By doing this, I was able to have a fuller understanding of what matters to the person and what conversations they enjoyed having.

Recognising the perspectives of different individuals connected to the person living with dementia can be a useful process in understanding the benefits and possible disadvantages for the person taking part in the research (Clarke et al. 2011). All the legal representatives of the participants were asked if they would like to be part of this process in preparation for the person with dementia to participate in the research. However, everyone said they were happy for the manager to do it on their behalf. Once consent was given by the person living with dementia, they, the nursing home manager and I had a conversation about the risks and what steps should be in place should that risk happen. For example, one person said they like to listen to music if they became upset, while another claimed that there's 'no chance' that he would find this topic upsetting and could not identify any risks.

The nursing home manager and I spoke with each person privately to ensure that they themselves felt that they would experience more benefits than disadvantages

in taking part of the research. We asked each participant about what they thought may be the advantages of taking part. All participant at this point said that they would find the conversation interesting and would enjoy speaking about sexual expression. No person thought there would be any disadvantage, but we spoke about what they would like to happen should the person with dementia become upset. Additionally, it was likely that the person with dementia and the nursing team had already developed strategies and responses for managing risks. Along with the manager, I gathered sufficient information about how the person usually expresses feelings of distress and how they usually respond too and manage having sensitive conversations or how to respond to the person if they get upset.

I also spent time getting to know the nursing team participants, by working alongside them before they took part in the research. I ensured I spent at least a day with the participant before having a conversation conducting observations. For the nursing team, all participants were informed that the conversational interviews and observations were not coming from a place of judgment, but were used as a way to understand how nurses experience caring for persons living with dementia, and how they experience and respond to sexual expression in persons with dementia. Nursing team participants were informed that this research was hoping to gain some understanding on sexual expression in persons living with dementia and the nurses' experience of caring for people with dementia. Thus, participants were aware that they were contributing to a new body of knowledge and to how we can improve the care of persons with dementia and job satisfaction for nursing staff.

Participant's also deserved assurance of what would happen with their consent forms and data. The participants were reassured that signed consent forms with the participant's name and signature was for my use only and was not shared with anyone else or used for any other purpose other than to gain consent. All participants were given a pseudonym to protect their identity and they were informed of this, so they know confidentiality is maintained. Once all the transcripts and field notes included the participant's anonymous name, I asked if I could share

the transcripts with my supervisors in a peer review process, which all participants gave consent for this. Private conversations with the participants were recorded and the digital recorder was transported in a lockable filling case which only I could access it. When I was not working in the home the recording device was stored in a locked filling cabinet within QMU. All recordings were deleted as soon as I finished transcribing the conversational interviews. In keeping with the Economic and Social Research council (ESRC 2020), all data that was collected was transferred onto a laptop provided by QMU. This laptop was locked, and password protected, and I was the only person to have access using my QMU username and password.

So far in this chapter, I have described the nursing home where the research took place and I have introduced the participants who volunteered to participate in this research. I have also discussed how I carried out the recruitment part of the research and aimed to be inclusive to all the nursing team and persons living with dementia.

Sensuous Knowing: Capturing Experiences of Sexual Expression

Principle: 'Embodiment will be highly valued, and the researcher will pay close attention to emotions, senses and desires throughout the research.'

Conversational interviewing is an approach used by research interviewers to generate verbal data through talking about specified topics with research participants in an informal and conversational way (Given 2008). Conversational interviewing foregrounds aspects of sociability, reciprocity, and symmetry in turn taking found in mundane conversation (Given 2008; Cridland et al. 2016). I thought conversational interviews with persons living with dementia was an appropriate method for this study, creating an environment whereby the participants can share their and experiences. Conversational interviews also can develop trust between the participant and the researcher, as the discussion becomes a two-way conversation, rather than a feel of an interview as such, which is a vehicle to access the meaning of an experience (van Manen 1997). To enhance inclusion, participants who have dementia were provided with the opportunity to have a significant

person present with them for support during the conversations, as having a close friend or family member may make the person living with dementia feel more comfortable (Scottish Dementia Working Group (SDWG) 2013). I continually asked the participants throughout the research period if they would like to have a member of their family or a friend present, however, no one took this option up and everyone agreed to their conversational interviews being recorded and transcribed. The conversations lasted between twenty minutes and an hour and ten minutes and took place in either the person's private bedrooms or in the conservatory area. After the conversation, the nursing home manager, spoke with the participants with dementia to find out if they enjoyed taking part in the research.

I ensured there was no strict interview schedule as I wanted the conversation to develop naturally. With that said, to ensure the conversations remained within the focus of the research question and addresses its aims and objectives, I produced a set of probes/questions as a guide (*see table 4*). With the participant's consent, I recorded each conversation and then transcribed the recording word by word.

Table 4: Conversational Interview Topic Guide for Persons Living with Dementia

Topic Stem	Example probes or questions
Experience of residing in a nursing home.	<p>What aspects of life do you miss most since residing in a nursing home?</p> <p>Is there anything that could make your time living in a nursing home a more comfortable experience?</p> <p>How do you feel nurses respond to the way you express yourself?</p>
Emotions, senses and desires	<p>What emotions and desires are important to you while living in the nursing home?</p> <p>How do nurses consider your emotions and the way you feel?</p> <p>Does how your feeling ever get misinterpreted?</p>
The body	<p>Does your body feel differently while living in a nursing home – can you tell me more?</p> <p>How does it feel when nurses touch and move your body?</p> <p>Has anything you have done with your body been misinterpreted by the nurses?</p>
Intimacy	<p>What does intimacy mean to you?</p> <p>Has intimacy changed for you since you have been in residential care? If so, can you tell me more?</p>

Sexual expression	<p>Do you feel you are able to talk to nurses who care for you about sexual expression and intimacy?</p> <p>In what way can nurses support you more?</p>
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I showed this topic guide to participants to give them a feel and an example of the potential conversation topics they may be engaging with. Generally, I envisaged that conversations would have started broadly about the participant's experiences of living in a nursing home and the conversation would gradually, at the participant's pace and direction, evolve into a conversation about the body, intimacy and sexual expression. The aim of this was to enable conversations will lead on to discussing about intimacy and sexual expression in a sensitive way and only if the person wishes to discuss this. I also wanted to pay close attention to the participant's sensuousness. Understanding emotions, senses and desires that shaped the participant's experiences was something I wanted to capture. Interestingly, the conversations I had with persons living with dementia, did not follow this guide. The participants themselves introduced the topic of sexual expression very quickly in the conversation and they directed how the conversation developed. I ended up not using this guide in any of the conversations as the participants chose what they wanted to speak about. It seemed that having formed a relationship and had various opportunities to get to know one another and talk about the research, prior to data collecting, made the participants feel comfortable to speak about sexual expression early in the conversation. Nevertheless, many of the questions in the guide were covered by the participants, just in a way and in an order that they determined.

Prior to having my first conversational interview with a person living with dementia, which was Frank, I was nervous and apprehensive. After working through the ethics application, being encouraged to think very carefully and delicately about including adults with incapacity, I assumed that I would need to be very sensitive with the conversation and slowly introduce some questions and use my skills and judgements to see how far the person living with dementia wanted to take this

topic. It took me by surprise how open participants were with sharing their experiences and how much participant's themselves directed the conversation towards sexual expression at the beginning of the conversation. For example, Archie led the conversation straight to speaking about sexuality (2nd March 2020):

Archie: *So your research is looking at older people and sexuality, is that right?*

Karen: *Yes, I am look at sexual expression in persons living with dementia in nursing homes.*

Archie: *Uh huh, that's interesting... we never speak about sex in here.*

Karen: *How do you feel when you hear that it could be something we talk about within a nursing home like this?*

Archie: *Good, it's an important part of life isn't it? Just like eating and sleeping.*

I invited the nursing team participants to take part in both participant observation and conversational interviews. Participant observation is one of the main ways to collect data from the culture under study, and observers try to become part of the culture, taking note of everything they see and hear (Holloway and Wheeler 2013). Participant observation was useful for me to obtain the context and culture of the nursing home. It also provided to be a useful method for me to capture the characteristics of each of the nursing team participant and getting to know them in the context of their work. The observations were pivotal in producing material for me to create the nursing team participant's interpreted descriptions (*see Chapter Eight*). It was clear that any information taken during observations would only be from the nursing team participants, who agreed to be observed. All staff, every resident and any relatives or visitors were ensured that no data was extracted from the persons living with dementia. Nurses who agreed to find out more about the research were told before they agreed to participate, and on each encounter thereafter, that observations could have been stopped at any time. The observations took place in communal areas of the nursing home, such as corridors, the nursing stations, dining room, living room, gardens and outdoor space, unless privacy is needed. Observations ranged from ten minutes to an hour. No

observation took place during any form of personal care giving or private moments. There was only one time a period of observation had to stop unexpectedly. This was due to a resident living in the home needing urgent care and medical attention in the lounge. When this happened, I stopped observing immediately and ensured the person received the correct help. When I was confident that the person was getting the appropriate care, I comforted and spoke to other residents in the lounge.

To help capture my observations I created a guide that I adapted from Merriam's (1988) participant observation guide in combination with the see/hear, feel and imagine framework (Dewing et al. 2014), which is a popular practice development observation tool. Merriam's guide encourages the researcher to: (1) focus on the physical environment; (2) create descriptions of the participant(s) I was observing and (3) describe interactions and activities. The guide also encouraged me to describe the role and influence of myself, in addition to what I am feeling and thinking during the observations. By incorporating the two guides I created an observation framework (*Appendix 11*) which enabled me to capture what was happening, but without being too rigid and structured like I was looking for something in particular.

Conversational interviews with nursing staff was also an appropriate and valuable method for this study, creating an environment whereby participants shared in-depth descriptions of their experience of practice. The interviews were unstructured again so participants could tell me as much or as little as he/she wished, and they led the conversation in their own direction. Even though unstructured conversational interviews are accompanied by an aide memoire, there was no predetermined questions. This allowed flexibility and made it possible for me to follow the perceptions, interests and thoughts of the participants rather than my own assumptions (Holloway and Galvin 2017). The participant determined the interview length time, and it was made clear to them that they could have decided to stop or terminate the interview at any time. Conversation length time ranged from thirty minutes to approximately two hours and fifteen minutes.

To promote participant's comfort, I invited them to choose where they would like the interview to take place. Some chose to have their conversational interview in the office area I was given during my time working in the nursing, some chose the conservatory, some the football memories room whilst others chose the quiet sensory room that the nursing home had. I offered participants the option of an interview outside the nursing home if they felt more confident and comfortable having outside their work environment, but everyone opted to have their conversation in the home.

The conversations with the nursing team generally had an interesting critical and reflective dynamic to them. Much of the conversations were about the participant sharing their experiences of sexual expression. It was clear that for many of the nursing team participants, having a conversation with me was the first time they had spoken about sexual expression in persons living with dementia. Participants started questioning their own assumptions throughout the conversation and were grappling with new thoughts and ideas. I have included two examples of this below:

Example 1 (3rd February 2020):

Tanya: *Well, you have opened my eyes with just this wee [small] conversation and gave me lots to think of. I have never thought about that before.*

Karen: *You have given me a lot to think about too. I hope this has been helpful and enjoyable.*

Tanya: *It's been good. I thought I would maybe get embarrassed, but you are very easy to talk too and you have opened my eyes and I have been asking myself a lot of questions. The main thing I am going to take away is that how would I feel if it was me living in a care or nursing home. How would I feel about my sexuality?*

Example 2 (4th February 2020):

Mark: *I have never actually thought of the sexual side with dementia before. That is why I think it is great that you're doing this you know, because it really gets you thinking. I have never thought about it before. But why haven't I ever thought about it before? What is stopping us from talking about it and including it into our care and care plans? You don't*

think about older people and sexuality. You just assume they don't have sexual feelings, but where does that come from?

I asked participant's if it would be possible to have a follow up conversation after I transcribed their previous conversational interview. I wanted to offer the participants the opportunity to member check their transcripts, so the participants can determine whether I interpreted the previous interview correctly. This process also allows the participants to add more depth to their experiences and stories (Streubert and Carpenter 2011). Only one person wanted to read their transcript back. However, I had some follow up conversations with Susan, Helen and Erin as they wanted to talk to me more about their thoughts that had developed after their initial conversational interview. They gave consent for the follow up conversations to be recorded to be used for the research.

Radical Reflection: Interacting with the Data

Principle: 'Researcher is aware and explicit how own views (prejudices) can influence the research process and interpretations of text but will not attempt to bracket them. Rather the researcher will engage in radical reflection throughout in order to be to bring together the perspectives of others and self.'

This section describes the process I used following each period of engaging with participants experiences, which involved being reflective and reflexive, writing field notes, transcribing the conversational interviews, and starting to reflect on the research material through the lens of the four existentials. Despite it being obvious now, at the time I did not realise that I was dipping my toe into the deep ocean that is phenomenological analysis. However, it soon became clear to me that by interacting with the data I was entering a first-level analysis. I had described in my ethics application and research protocol that data analysis would occur concurrently with data collection and will continue when data collection was completed. However, reflecting back, this claim was just a little more than words on a page. Starting to interact with the data along after conversations and observations

allowed me to make sense of what was being gathered and reflect the interactions I had with the participants and what experiences they shared.

Transcribing the conversational interviews was more than just an administrative task. It was a meaningful activity which provided me with a steppingstone for getting closer to the experiences the participants had of sexual expression. I chose not to use any transcribing tools or programmes such as NVivo to assist with this process. I began transcribing as soon as I possibly could and completed the transcription within 24-48 hours after having the conversation, as I wanted to keep the 'feel' of the conversation alive. I wanted to work through this process on my own and to use this process to connect with the text and allow this time to not only get the spoken words on paper, but to reflect on what was being said. I felt that I was the most appropriate person to transcribe the conversational interviews as I could pick up on the mood and atmosphere of the conversation. When I was immersed in the transcript, I was sensing, moving, responding and resonating what the participant was saying with my whole body. Like Finlay's (2014) experience, I was not just 're-remembering' my encounter with each participant, I was 're-embodiment' it.

Throughout the entire research experience, radical reflection was an important principle for me to adhere to. Prior to each day 'in the field', after a set period of observation, and after each conversation, I felt it was important to bring my pre-assumptions up to the surface so I could become fully aware of them. This allowed me to, as much as possible, differentiate my experiences, thoughts and feelings to those of the participant's so that their voices and experience do not get muddled amongst my own reflections. At the end of each observation or conversation, prior to transcription, I would reflect on the experience from my point of view. I created a flexible template to guide these reflections (*Appendix 12*). This was also useful for me to keep a reflective account of my experiences of the research process. Writing the descriptions of each experience and interactions from my own perspective gave me the opportunity to capture my thoughts and feelings of what was said or done.

Having my reflections, and the participant's transcripts, gave me the material to delve deeper into the analysis (Finlay 2011; Wareing-Jones 2016).

Existential Discovery: Immersing myself in the Data

Principle: 'The four existentials (corporeality, relationality, spatiality and temporality) will be used as guides for discovery and reflecting on human experience.'

I now move onto how I took the analysis to a deeper, more formal level. According to van Manen (2002), a sound phenomenological research study always does two things: (1) they provide concrete interpretations of lived experiences, and (2) they offer insightful reflection on the meanings of these experiences. This is what my aim was for analysing the data I was able to capture during the fieldwork. In this section, I describe how I used the four existentials, along with the Sensuous Framework, for reflecting on the participants experiences and coming closer to describe the phenomena of sexual expression as understood and lived out in a nursing home setting by nurses and persons living with dementia.

Rather than reviewing all the data together or looking at each existential across all the participants in turn, like Rich et al. (2013), I worked with each participant's data separately before moving on to the next. I felt that by doing this I could retain more of the person-centred nature of this research, allowing each participant a clearer presence and voice. To achieve this, I tried as best as I could to focus on each person individually as if they were the only participant in the study. This became harder the further I progressed with the analysis. There was always a risk that the experience and narrative of a participant may influence the description of the next participant, and I would automatically start to make alignment and connections between participants. To minimise this risk, I ensured that I took at least 24-36 hours between finishing a draft of a participant's description and starting to engage with the next participant's data.

In the first stage of this process, I looked at each transcript, following this with a more detailed focus on the four existentials in turn. This meant that I read each

participant's transcripts and field notes they featured in, six times. The first read was 'getting into' the person's experiences and I would read it as a whole from start to finish. The next four reads were focusing in on the four existentials of relationality, corporeality, spatiality or temporality in turn. I designated a coloured pen to each existential and I would highlight the words, phrases and experiences that related to that existential.

During this process, I was also reading each transcript and the field notes using the Sensuous Framework. As described in Chapter Four, I believe that experiences that strongly ignite our emotions, penetrate our senses and inflame our desires, are powerful and meaningful. Tapping into our feelings, sensations and pleasures can provide us with knowledge on human experiences and certain phenomena, such as sexual expressions. I wanted to understand what sexual expression meant for the person as sensuous beings and how it connects to our sensuousness. Therefore, when I was focusing on corporeality, I paid close attention to participant's emotions, senses and desires within their transcripts. In other words, I was being attentive to the participant's sensuousness. Once I had read the transcripts, focusing on the existentials one by one, I then read the transcript as a whole again, to get a strong sense of the full picture of the participant's experience before I would start my phenomenological writing.

Writing in the Dark

Principle: 'Researcher uses own knowledge, senses, emotions, intuitions and imagination to understand nuances embedded in the lived experiences.'

Phenomenological writing is not just externalising internal knowledge, rather it is the very act of making contact with things in our world (van Manen 2002). In this sense, to do research is to write and the insights achieved depend on the right words and phrases, on the styles and traditions, on metaphor and figures of speech, on argument and poetic image. Writing is not solely an academic exercise, but an embodied lived experience in itself (Finlay 2014).

Getting in the space for phenomenological reflection and writing was a challenging experience. It felt unfamiliar to any form or style of writing I had engaged with before. In doing phenomenological research, through the reflective methods of writing, the aim is not to create technical intellectual tools or prescriptive models for telling us what to do or how to do something. Rather, a phenomenology of practice aims to open up possibilities for creating formative relations between being and acting, between who we are and how we act, between thoughtfulness and tact (van Manen 2002). Thus, I needed to find a zone which enabled me to begin stage one of the analysis, which was to 'insert' myself into the transcripts (van Manen 2002), allowing my imagination to flow and write in a way that was expressive, thought-provoking and allowed the reader to feel and touch the lived experiences.

The time I was moving into the data analysis was concurrent with the peak of the coronavirus pandemic in Scotland. The university, where I was based was closed, which meant I needed to do all my studies from home, which was something I had never enjoyed and always felt my productivity was lower than when I was at my desk in the university. Further, my contribution to clinical practice considerably increased at this point. The nursing home where I work clinically had a severe outbreak of the coronavirus. In order to continue to care for the older persons living in the home and to keep my family safe, when I was in my house I was self-isolating as best as I could from the three other members of my family. Therefore, I was confined in my bedroom and had no choice but to make it a suitable environment for PhD work. I had no desk, limited resources and very little space to move around. The physical environment was not 'conducive to writing' (van Manen 2014 p. 358). It was unclear of how long I had to get used to the situation, so I needed to adapt the space around me to begin writing.

Initially, I was still trying to keep my 'normal' PhD routine by getting up about 6:00 in the morning, jump in the shower, have a morning coffee and open up my laptop ready to write. However, I could not get any words on a page or if I could, it was going at a snail's pace and felt cumbersome. If I were working clinically the day before, I could not switch off my brain from thinking about the events from that

shift. I could answer emails no problem and engage in online meetings, but when I tried to focus my attention on delving into the transcripts and field notes, and then writing phenomenologically, I felt I was running on a low battery. My eyes would feel heavy and I could feel myself wanting to drift into a sleep. I was aware my posture was slouched and engaging my fingertips to my keyboard felt like a monstrous effort. I then became frustrated that my efficiency was low.

I decided to take a new approach to my working day where I was focused on writing. My first change was that I switched my morning alarm off completely and woke up when my body wanted too. Even when I woke up, there was no major rush in hoping out of bed. I would take my time in coming into a new day. I'd take stock check of the day ahead, guess what the weather was like from the small break of light trying to burst through the curtains, and allow my entire body to waken up and not just my eyes to open. I was very grateful that someone would bring a cup of tea to my door and I would then play some music and take some time to enjoy my first hot drink of the day and use this time to reflect on whatever was in my head at that time. When I began to feel restless, I would then hop in the shower which always makes me feel refreshed and more energised.

As I was confined into my bedroom, I would try my best to arrange the pillows on my bed so I could sit in a comfortable sitting position. I would sit crossed legged on the bed, with my back against the headboard and my laptop would sit on a pillow on top of my lap at the correct height. I also filled the room with music. It could not be my favourite collection of pop music and classic hits, as I would get distracted and sing along. I found instrumental, spa-like music helped me enter to take my thoughts elsewhere. The volume had to be just right. It could not be too loud that it would overpower my other senses. It needed to be soft background music, quiet enough that I was able to focus on my thought process, but able to hear it so my imagination could flow away with the music and I could enter the space, where the hustle and bustle of a busy household were no longer distractions. I became focused and connected to the transcripts, which made me feel reconnected with the participants.

I was then experiencing afternoons and evenings where time flew by. Words were getting written and any interruptions and distractions were most unwelcome. I found immersing myself into the transcripts and field notes exciting and adventurous, especially not knowing what was going to emerge from it. I felt the desire to write was ignited (van Manen 2014, p. 373). Although, I was apprehensive, I had to 'let-go' and just let the writing lead me into the unknown. I was getting lost into a phenomenological world, which filled me with uncertainty and excitement. It felt peculiar writing without knowing what I was aiming to achieve. I had to trust the process and let my wonder guide me.

After my self-isolating period, I maintained my new routine. The only difference was that I would go for a walk in the fresh air for some exercise and reflection time before getting in the space for writing. I was also able to use the dining room table as my temporary desk. Once I entered that space, I found it difficult to get out of it. I would be writing deep into the night and again, I would listen to my body and not stop until my eyes felt weary from staring at the screen or I needed to rest my thoughts. In a way, I am amazed that this routine never occurred to me before. Naturally, I am much more of a night hawk than an early bird, but I considered this unprofessional for work. Nevertheless, I realised that going into the darkness of phenomenological writing needed to be at a time where I was naturally at my best and was most energised, vibrant, and focused.

This first thing I wanted to do was to make each participant's experiences come alive with words. I wrote descriptions for each person who participated in this research as I wanted a part of their character to be felt by the reader. Each participant is a unique individual, and they are more than their experiences of sexual expression. Thus, I wanted to give a flavour of what kind of person each participant is. I did not want someone's important experiences to be affixed to only a fictitious name. Presenting a short narrative, telling the reader something unique about each person before going into their experiences of sexual expression.

Following on from this, I focused on each of the four existentials in turn and wrote my interpretation of how each of the existentials were presented for each participant. When I was reflecting on the field notes and/or transcripts using the four existentials, I became aware that the existentials of lived body, lived relation, lived space and lived time are not fixed, or boxed into their own compartments. Some elements of the participant's descriptions were very clearly connected to more than one of the four life existentials. This determined how I presented the existential reflection for each participant as it will become clear that I present the order of the existentials in a different order for each participant. The existentials did not produce sections or themes of the lived experiences of sexual expression, but rather a narrative, where the existentials linked and intertwined with one another.

Within the existential descriptions, I used some of the raw data, which captured and revealed how each existential related to the phenomena of sexual expression. They were also seen as the 'gems' for developing and writing the phenomenological text (van Manen 2014). At the end of this process, I was closer to the experience of sexual expression in persons living with dementia for each participant. Therefore, I concluded each participant's writing with suggestions and interpretations for the essence of sexual expression in persons living with dementia and the meaning for each participant. I then brought these together to develop a summary meaning and essences of persons living with dementia, which will be presented in the next chapter.

Conclusion

This chapter began revisiting the research question and the aims of this project. My methodological principles, presented in Chapter Six, were made real by working through the practical aspects of the research. Through discussing how I fulfilled my methodological principles and engaged with the nursing home and the participants I also addressed important ethical considerations so I could explore the topic of sexual expression in a sensitive and respectful way and be inclusive persons living with dementia who may not have the capacity to provide informed consent. For me, giving people the space and time to share their story and to hear their

perspective of this phenomenon was not only important for my values and beliefs, but pivotal in contributing to being person-centred with those living with dementia.

In Chapter Eight, I move onto the findings and I present the participants' descriptions and experiences of sexual expression, and my interpretations of the meaning and significance of sexual expression in persons living with dementia for each participant. Through synthesising each the essence of sexual expression from each participant, I will offer a description of the phenomenon of sexual expression, which has been derived from the lived experiences of the participant's involved in this research.

Chapter Eight: The Meaning of Sexual Expression in Persons Living with Dementia

Introduction

In this chapter, I describe and interpret the meaning of sexual expression as understood and lived in the nursing home setting by nurses and persons living with dementia. Using transcripts and the field notes, I crafted detailed descriptions for each participant through the lenses of the four existentials of relationality, corporeality, spatiality, and temporality (Merleau-Ponty 1964). At the end of each person's descriptions, I present a summary of essences which captures, as well as I could, the heart of their experiences. I initially focus on the nursing teams' experiences of caring for persons living with dementia who express their sexuality and then attempted to synthesise the central meanings of sexual expression in persons living with dementia as experienced by the nurses. Following this, I then focus on the persons living with dementia experiences of sexual expression, where I attempt to synthesise the essential meanings of what it feels like for persons living with dementia to express their sexuality while living in a nursing home.

The aim of this chapter is to describe as closely possible the meaning of sexual expression in persons living with dementia from both the nurses and persons living with dementia's experience, keeping in mind that it is my perceived and interpreted description. It is through reflection and language which we can access and gain a strong flavour of the experiences of others. Therefore, through radical reflection and phenomenological writing, I sought to come closer to answering the research questions:

What is the meaning of sexual expression in persons living with dementia who live in a nursing home setting? And;

How is sexual expression experienced and understood by the nurses providing care?

Lived Experiences: The Nursing Team

Valerie

Valerie has a warm nature, which I immediately noticed when I met her. She was the first nurse I was introduced to by the nursing home manager. As I introduced myself to Valerie, I put my hand out to partake in the formal greeting tradition. Valerie keenly took my hand and greeted me with a smile. I felt that a professional handshake was a little decorous for Valerie's taste. I got the impression that had this not been the first time I met Valerie she would have greeted me with a hug. I spent the next day with Valerie, which consisted of chatting to residents over cups of tea, helping staff with activities, and having informal chats with Valerie. Valerie had just recently been promoted to a senior position in the nursing team. She would frequently check-in on staff in the other houses to offer a helping hand and show support. Throughout the day Valerie was facilitating and directing the carers in ensuring the residents in the house were receiving good care and enjoying their day. Her understated enthusiastic attitude seemed to spread through the house. A relaxed and joyful atmosphere filled that specific corner of the care home. I wondered if this light-heartedness was common for this house or was it Valerie's influence that created the atmosphere? The residents in this specific house appeared to be having a relaxing and enjoyable day, which mirrored Valerie's persona.

I was also observing Valerie's relationship and interactions with staff who she was working with that day. They would go to her for advice and take on board whatever she said. She did not raise her voice when Valerie gave a firm direction to her colleagues. Her tone was gentle, and her manner was very polite. Valerie has been a nurse for over eight years and really enjoyed working in the nursing home. I could tell that she had built a connection with the residents. During a quiet spell of the day, Valerie sat next to the residents who were in the lounge and engaged in conversation with them. She sat on the couch in the lounge opposite me. The resident she sat beside smiled and took her hand immediately. They started a friendly chat together, like they just picked up from wherever they left off. Valerie

engaged with the woman with some friendly banter. They engaged in a conversation that made it clear they had built up a relationship where they could have an element of tongue-in-cheek throughout their chat. They laughed together and Valerie listened to every word the resident said to her. She was getting interrupted a couple of times by telephone calls and colleagues coming to ask her questions, Valerie always returned to her conversation with the person who she was sitting beside.

Relationality

The relational aspect of sexual expression was visible throughout the conversation with Valerie. She said that she initially felt uncomfortable seeing displays of affection between married couples and would not be sure on how to respond to that situation. For example, if a husband and wife were sharing an intimate moment, Valerie felt uncomfortable. She continued her story by telling me that over time she comes to terms with the fact that they are a married couple and it's acceptable for them to have a kiss and a cuddle. Relations between two residents that were bound in matrimony made sexual expression acceptable for Valerie:

*I think as time went on, people were more supportive of it... I think people thought they might be **jumping on each other** every half an hour in the lounge and whatever, ehm.. but I think once people realised they **are just a normal married couple, and** they are going to maybe want a wee kiss or a cuddle or whatever...*

Valerie positioned herself as an advocate for persons living with dementia who she provides care for. Talking about two persons living in the home forming a relationship, or residents who enjoy masturbation, Valerie mentioned the influence and connection with resident's family members. Thinking about supporting resident's sexual expression, she told me that when she writes care plans and make important decisions, family members have to be involved, especially if the person with dementia has an 'adults with incapacity' (AWI) form in place. The relationship between Valerie and the resident's family members was a struggling point for her:

*...because you do care reviews and social work reviews and **you're going through the care plan with the relative as well and that is always kind of in the back of your mind when you are writing the care plan that the residents son or daughter might be reading it...** and if you have 'your dad would like to masturbate every afternoon when he is in his own room', that could be a shock to them as well and it's that, you need to **because everything we do involves the family and you think a lot...**I don't know if a lot of **their family** would be happy about having things like that in their care plan and ehm... again I don't know why that would be an issue, I don't know why that is, it just...it just is that taboo.*

She reflected on times that persons living with dementia who lived in the home would express themselves sexually and Valerie would use distraction techniques or perhaps change the subject quickly at times to respond to sexual expression. Valerie said that by distracting the person or ignoring sexual expression could negatively impact on the relationship between Valerie as a nurse and the person. She believed this could make residents feel that their emotions and desires are insignificant:

...the fact that you've brushed off that opportunity for them to open up and that person is left the whole day and they are like I really want to talk about this, but nobody is wanting to speak to me...** you know that they were expressing that they wanted to kind of get that sexual fulfilment, **you could then speak to them ehmm... I think we are missing opportunities and that we're closing that conversation down before the residents been able to express what they want to say.

Valerie spoke of her own embarrassment when sexual expression occurs.

'Brushing away' the scenario, meant brushing away the feelings of embarrassment for Valerie:

*I think your first instinct is to kind of just **brush it off**, and this is what I have done because **it's embarrassing and uncomfortable for me**, is just ehm.. just kind of went 'Oh no, lets changed the subject'.*

Corporeality

When talking about older person's bodies, Valerie discussed how she places a professional barrier or clear distance between herself and naked flesh. It has been ingrained in Valerie as a professional nurse to cover up the naked body as much as possible. When looking at a naked body, for example, assisting with showering, Valerie used her clinical nursing lens:

*I think when you're in work its always that thing you've got **this professional distance** as well in that yeah when you're **working and looking at someone's body**, I am always looking for **discolouration, bruises, lacerations** that kind of thing ehm... and like trying to maintain this dignity, **keeping someone covered up as much as possible** and that you're not looking at their body and thinking in a different way. You kind of **distance the person from their body... your distancing yourself** from their body. You're not distancing them from their body, **you are distancing yourself from their body.***

We spoke about significance of the bodies' 'private parts' and Valerie was talking about her experiences of nursing people where touching a person's genitals in a clinical sense is a common part of nursing 'work'. She was also reflecting on her own experiences of being naked and how much she would feel uneasy and insecure if a healthcare professional saw her in the flesh. Her breasts and genitals would be the first parts of her body that Valerie would want to cover up as she considers them as sexualised. However, she did not consider older persons' breasts and genitals as sexual:

*Yeah, yeah, cos I think that would be the first part, I mean if you **were naked** the first place you would cover is **your breasts and your genitals**, it is that thing that they are your **sexual parts**, but we [nursing staff] don't think of **older bodies as sexual.***

Spatiality

Valerie's experiences were influenced by the environment where sexual expression took place. Sexual expression occurred in areas of the nursing home which is considered private to the residents (e.g. their bedrooms), and other sections were communal living spaces (e.g. living room, dining area, conservatory, gardens etc.). Sexual expression was an issue in both private and communal spaces. Residents get compromised privacy and Valerie mentioned that there is always a conflict between giving residents space to be alone versus her duty to care to check up on them:

*...to think while, it's part of your job to check they are okay, but then **you are walking in and invading someone else's privacy**, it like can't be avoided, but it can be you feel..*

Temporality

Time was present for Valerie when she spoke about the different perceptions she has about an individual's sexuality and intimacy needs at different stages of life. She wondered why there seems to be more acceptance thinking acceptance the sexual aspects of persons when they are younger, but as persons age with time it seems to become more of a taboo and something that is considered as atypical:

*...well if you think it's acceptable to discuss young people having sex and married couples and that...so, **so when does it become unacceptable, what age is the cut off...** like for there to be unacceptable, **like why is there this age limit?** And.... Well I have never really thought about it until we started thinking about it for you [the researcher] coming here... **but at what time in our life do we stop thinking it [our sexual expression] is normal?***

Sexual expression was also considered more problematic for Valerie to respond to if there was less time between each expression. In other words, the more frequent someone expressed sexual needs and desires in ways that were seen as inappropriate it would be more problematic for staff:

*It would work there and then, but **then it could be 10 minutes later** he [the resident expressing himself sexually] could be asking somebody me again or someone else for the same favour and being sexually explicit again...*

The Essence of Responding to Sexual Expression for Valerie

For Valerie, sexual expression in persons living with dementia was an embarrassing phenomenon to think about and respond to. Valerie has the insight to realise that her own embarrassment creates barriers to providing good care when specific moments of sexual expression arises; however, lacked any drive to do something about it. Sexual expression between two residents was considered acceptable - if they were married. Traditional perceptions of a nurses 'duty of care' was prioritised over respecting their wishes and intentions for sexual expression. Older person's bodies and nakedness was not considered sexual by Valerie, unlike younger persons bodies. The views and perspectives of resident's families regarding sexual expression was considered more valid than the older persons.

Katie

Katie has a strong and vibrant personality. She is one of the most experienced nurses in the home and is often the nurse in charge when she is on shift. She exudes confidence and nothing seem to stress Katie. It took me a few interactions with Katie to feel like I was getting to know her. For the first couple of days I was working on the same day as Katie, she would be courteous and say good morning to me, and when I asked her a question, she would politely answer me, but I could just never get a conversation going. She was focused on her workload and the task in hand.

As I arrived in the home one morning, I walked into the staff room and Katie was sitting at the table having her breakfast. She was by herself. Katie then invited to me to sit down with her and have a cup of tea. As I sat down opposite Katie, I asked her how her morning had been so far. She told me she had been busy, but no more than the usual rush the morning brings. Katie then focused her attention onto me. She quizzed me about my research, asking me what it involved, why had I chosen the specific topic of sexual expression in persons living with dementia, why I had

chosen to conduct the research in the nursing home where she worked, what was I hoping to find and what I anticipated to do with the findings. I was very happy to answer her questions to the best of my knowledge, explaining the final two questions were at the time very hard to answer. Katie then started sharing with me her nursing career to date and various examples of when she has experienced sexual expression within her nursing practice. I did not record this discussion, but Katie gave consent for me to reflect on this conversation and use it as information for the research. Her break had finished, and she asked me if I would like to continue this discussion this afternoon after her lunch, as that is traditionally a more relaxed time of the day for her. Katie invited me to spend the day in the house where she was working to meet some residents and observe her at work. I accepted her invitation, and I was delighted that I was able to have an opportunity to continue in this conversation.

Spatiality

Katie referred to space in two ways during our conversation. She spoke about the prospect of an educational space for nurses to talk and learn about sexual expression. Katie was talking to me about how the nurses structure the care plans based on the activity of daily living (ADL's) and one of the ADL's is 'expressing sexuality.' Katie mentioned that this is the only place where 'expressing sexuality' was given any space within documentation but is often overlooked. For Katie, how to appropriately respond to scenarios of sexual expression needed to be discussed and taught in some way or another within nurse education:

*...there should be a **structure in some kind of nursing programme**, or... or even when you are coming into nursing in any form, as in even like care assistants... I'd have to figure out how to deal with it [sexual expression] because there's no... **nothing in a manual that teaches this. Nothing in the manual.** Again, it goes back to filling one of the ADLs **we are taught**, but **we are not taught that.** It's greyed out almost...*

Katie spoke about space in relation to the physical location of the residents expressing themselves sexually. She gave me two examples of men masturbating in the care home as one type of sexual expression she encountered. Resident's private spaces was significant in Katie's reflection on how to best facilitate and support this type of sexual expression. The person's private space meant that Katie could just let the older persons be alone.

*It [masturbation] would have to be something that **they do privately... in their own private space, behind closed doors.***

Temporality

Time emerged in Katie's transcript in relation to the frequency of sexual expression occurring. She thought nurses and care staff should be given guidance and education on sexual expression in older persons living with dementia due to the amount of times sexual expression occurs. The more sexual expression occurs, the more difficult Katie finds it to respond to:

*...I think it's because **I have come across it [sexual expression] a lot** and I do work with it because **it is part of most days in here** [the nursing home]. The more it happens the more difficult it is.*

Additionally, the existential of time appeared when Katie was reflecting on occasions where sexual expression was either humorous or threatening and troublesome for her. The amount of times sexual expression occurred contributed to whether she found it humorous or threatening:

*...because **he doesn't continually ask** for sexual favours like that, **its maybe a one or a two time ask a day** and then he will not ask for the **rest of that day, or maybe until the next day** or whatever... it's not as if he pursues it, its maybe a **one or a two thing** and that's it kind of finished with. Ehmm... yeah so there's kind of, almost as if there's no threat as such, but there was a higher threat in the other guy who would **be at you all day.***

Corporeality

Katie was comparing two examples of sexual expression. One where Katie felt a scenario of sexual expression was easy to respond too, and another that was more challenging. The older person's physical mobility was an important part that shaped her experience. Katie talked about when older persons would use sexual language and request sexual favours it was perceived as quite threatening by Katie, especially when the older person was mobile and had physical ability to walk around independently:

*...maybe because the gentleman in here is **not mobile**. So he can't, he can't pursue you. The other gentleman could. So **he would pursue** a member of staff, so **he would kind of chase them about**, which then became a bit frightening for that staff member... The other man, his verbal requests were never going to be fulfilled you know, as **he couldn't walk**...but the other one **could pursue, he could touch**, he could maybe chase, he could **grab**, he could maybe corner someone, you know.. So you've got, maybe a bit of a threat.*

Katie considered how an older person may enjoy having an intimate connection and wanting to be close to another human being. She spoke of the emotional responses that may evoke for someone and how being intimate is part of who we are as human beings in general:

*It's healthy and **it's nice to still feel touched** and a bit of **an emotion like that at that level**...because it is a **natural normal human desire**, I suppose, no matter how old you are.*

Relationality

The relationship between the nurses and the family members and/or power of attorney's (POA) of the person with dementia was prominent in the conversation I had with Katie. She felt that the voices of the family members were crucial in decision making when thinking about the older person who is living with dementia, so Katie would run things past the family to ensure they were happy:

We involve the families, the POA's. When you become someone's POA, you are looking after the person and making the decisions on their behalf and making decisions they would want for their mum or dad... ***that's why we listen to them and make sure they are happy.***

The second relational aspect for Katie was the relationships between two older persons living in the home. Katie felt that relationships in older persons in care homes were easier to get your head around if the couple were married. When grappling with ideas around residents forming relationships whilst living in a nursing home, Katie considered this to be more complicated:

*It weird isn't it? The minute you take away **the marriage part of it**, it just turns into a whole different conversation and a mine-field. There's acceptance to some degree if they're **married**.*

The Essence of Responding to Sexual Expression for Katie

For Katie, sexual expression in persons living with dementia is an aspect of dementia care that a nurse gets thrown in at the deep end and obliged to respond to with no guidance. There was a strong sense that Katie felt that sexual expression is *something* that should be *done* privately and is easier when out of [her] sight and out of mind. Sexual expression was considered normal and accepted depending on what the specific action was and if they were married. The perspectives of the families were important for Katie. Additionally, the frequency of sexual expression contributed to how challenging it became for Katie.

Susan

As soon I engaged with Susan, I noticed her bright personality and enthusiasm towards her job. Susan went into nursing straight from leaving high school. Her first post-registration job was working as a nurse in an acute general medical ward in her local hospital. She also had some district nursing experience. Susan wanted to expand and build up her nursing curriculum vitae, so she decided her next step would be to get some nursing home experience. Susan believed that nursing homes gets minimal attention within nursing education and was an area of practice she

seemed most unfamiliar with. She felt that she could not work up the career ladder, without having an appropriate understanding of the skills and expertise that is required from a nursing home nurse. She had a determination to give her best care with every shift she came on. I often heard Susan asking questions to more senior staff and talking about wanting to be signed up for many educational courses to enhance her professional competence.

Relationality

Susan felt that connection, socialisation and friendship with others was significant for the residents and it provided them with enjoyment. For Susan, relationships between the residents which were based on friendship were looked on positively. If a relationship between two older persons in the home became more intimate, staff, including herself, would react disapprovingly. Susan told me a story when a male and a female resident formed an intimate connection with one other:

*...say it was like [male resident's name] and we [the nursing team] would say 'leave her alone, stop pestering her, **just leave each other be**' and then that just distresses them out even more... like that kind of behaviour is like 'no, no sit down or whatever, just leave her, your pestering her' that kind of thing, and although that is still expressing sexuality, it's not ehm... overly sexual...**it is still a form of wanting to have that closeness**...we never asked the woman if she enjoyed his closeness. She looked happy with him, no sign of distress when they were together... Wrongly we assumed any more than a handhold was too much, **but we never gave it one thought that she might have liked and benefited from that closeness, ehm...we didn't give their relationship any thought...***

Additionally, Susan spoke about how sexual expression impacts on the relationship between the nurse and the resident living with dementia. Susan shared the general reaction that persons with dementia would receive from her if they expressed any sexual feelings. She told me a certain gentleman who if often seen masturbating,

would be labelled as being rude or perverted by the staff. This made Susan feel uncertain on how to respond to the situation:

...he got labelled again and again... he got viewed as dirty and most changed the way they [the staff] approach him, they didn't want to go near him as he was viewed as that dirty old man... I didn't know what to do...

Susan believes that nurses feel that having a discussion around sex, relationships and intimacy with older persons living with dementia presents great risks and goes against their safeguarding priorities. There was a sarcastic tone in Susan's voice at this point. She believed that the staff's fear and unwillingness to open conversations about sexual expression is unnecessary:

...they [residents living in the care home] should be protected, so oh my goodness, god forbid if someone mentions sex to them...

Temporality

Susan mentioned that there is often an assumption and a stigma that persons living with dementia retract back to their childhood. Susan believes that persons living with dementia often discuss their childhood memories and this strengthens the stigma attached to older persons living with dementia. When older persons living with dementia reflect on their past regularly, Susan believes this provides barriers for discussing sexual and intimate wellbeing:

*...they have dementia so there's that kind of ehm... that stigma again that they you know, **they are retracting back to childhood** and they are **working backwards in their past almost** so ehm... well you don't have this conversation with children so people believe you can't have that conversation with people with dementia...*

Spatiality

Susan referred to the environmental space of the nursing home how and the importance of residents having access to private space. For Susan, private spaces

are a crucial for responding to scenarios of sexual expression. Private spaces such as the resident's bedrooms and bathrooms were important for Susan as she could direct residents as privacy was seen to protect the person's dignity:

*Like when a gentleman wants to masturbate, **he often does it in the lounge...** I said to him you know **you can't do that here** and ehm... we usually get him **into the bathroom** to get him sorted kind of thing, **or his room, as long as it's private...***

Corporeality

The human body was addressed in Susan's experiences through older persons living with dementia touching other people's bodies. Susan said that some forms of affection were viewed as sweet and caring, but if it develops to anything more then it gets challenging for her. A kiss moved physical touch and closeness into an uneasy territory for Susan. Any form of touch between two residents that exceeded a hand hold or a kiss on the cheek was challenging for Susan:

*... say another resident we have with dementia, actually two residents, they would be **sitting and kissing and touching each other's legs** you know ehm... these two residents can be **very touchy feely**. No one minded them **holding hands or maybe a kiss on the cheek...** but even if I saw a resident **kiss another resident**, you know, **like properly on the lips** or anything more, if it was done in ehm like in a romantic way I wouldn't know what to do, so I just would encourage them to **just hold each other's hand** because I don't know how to address it any other way.. You see everyone else getting uncomfortable with their **affection towards another**.*

The Essence of Responding to Sexual Expression for Susan

For Susan, different forms of sexual expression in persons living with dementia was met by nurses with a spectrum of acceptance, with gentle expressions, such as handholding viewed as acceptable and some expressions being unacceptable, such as sexual contact between two persons with dementia. Susan felt that the staff's uneasiness and unacceptance of sexual expression overpowered the benefits for

persons living with dementia. If sexual expression could not be stopped it was preferred to be contained in a private space, so it was out of potential harm's way. Susan felt that because persons living with dementia are often viewed to be retracting back to their childhood, staff believed that you should not talk to persons with dementia about sex and intimacy.

Helen

Helen is a senior care assistant working in the nursing home. She holds a lot of experience as she had been working in care for most of her working life. She describes herself as the most 'mature' member of staff. Helen was very experienced and had spent many years working in a nursing home. She was a calm voice that deescalated situations and provided staff with a lot reassurance with the situation. I never saw Helen becoming alarmed or rush around in any panic that often was created during busy and challenging moments. Many staff would rely on Helen for help and support and she would always make time to provide others with assistance.

Helen enjoyed peaceful alone time during her shifts. Rather than spend time in the staff room on her breaks, Helen would choose to either sit outside if the weather were decent, or she would find a quiet space in the home. She invited me to join her for lunch one day when I was getting to know her. Helen had two cigarettes during her break, but smoking was not the only reason for Helen to be outside. There could be a lot of hustle and bustle in the staff room during lunch time, but Helen wanted to experience peace and quiet, and being outside gave her an opportunity to gather her thoughts, especially she is experiencing a shift where she is rushed off her feet. She said that this made her feel re-charged and ready for whatever the rest of her shift would bring. An older person living in the care home would come and join her, if it was a nice day. I saw this a couple of times during my fieldwork spending time in the nursing home. They would just sit beside one another, sometimes not even talking, they would just be watching the world go by and enjoying the stillness that nature provided.

Temporality

Helen referred to temporarily when she was speaking about the ever-evolving knowledge that is emerging within dementia care. Helen reflected on her career and was sharing her experiences of a time where knowledge on dementia and wellbeing care models were limited. Helen always described knowledge on sexual expression in persons living with dementia as something she could see emerging in the future:

*We are **learning so much as each year goes by...** we're becoming able to understand situations and people's needs and wants and wellbeing **and before then**, there was just, well nothing. So this might, **you know sometime in the future**, this might be there might be something that people who can still have a conversation, who might be interested in talking about things like sexual expression, their sexuality and wanting intimacy, maybe when **my generation or younger generations** go into care homes ... and that will be quite interesting to see what comes out of it **in the future**, because it should be something involved in dementia care...*

Relationality

Helen felt that having an established, trustworthy relationship with the family would help have conversations sexual expression. She saw incorporating sexuality care plans potential if the staff and relatives work together in the best interest of the person with dementia:

*I think it is **so important not to cut them [families] off**, never cut them off and I don't understand why people can't get that if you talk to their families, and their families talk to you, **then you are working together rather than against each other**, so if something came up, an issue came up, ehm... then you would be able to feel comfortable, then they would know we have their [the residents] best interest at heart, that we are understanding and we are actually listening to their voice and also **the families...the families feelings**.*

Helen felt that focusing on the family's wishes and perceptions could also be problematic. She shared a story of two residents she was caring for formed an intimate relationship. Helen said that this caused the family distress and many staff would 'side' with the families wishes. Helen saw that the two older persons expressed happiness a when they were spending time with each other and she felt she was not providing the best care she could have when they were encouraging to separate the older couple due to their families wishes:

*Actually **two residents** in the home and they both had dementia, and they used to **lie on the bed next to each other**, that's all they did, **they thought they were boyfriend and girlfriend**, and they let that happen because they both seemed happy and ehm, the people that were more upset were the families, **they got upset when they seen their dad, their mum**, on top of the bed, but they were happy... and to stop that it just seems, wrong, because they weren't in any danger and just getting that **comfort and joy from one another...***

Helen wondered if she was too focused on the family and did not take into consideration that close relationships, or sometimes intimate relationships, contribute to older person's wellbeing and happiness:

*I think people, **both nurses and carers too can just write them** [older persons living with dementia] off far too quickly and ehm.. I think it is important to remember that they are adults and they do have an illness, but they do have rights still as individuals, and **we are not here to tell them what to do, we are here to ensure them that they are safe and that they are having a happy day, a nice life, for what they have got left**. That's, that's my goal. Ehm.. I think some people, sometimes talk to them like they shouldn't even be thinking about sexual things or shouldn't be doing things masturbate or **have relationships** that ehm... **we are not their boss** and this is their home and I think that is really really important to remember.*

Corporeality

There were moments where Helen shared moments when older person with dementia were touching their genitals, making flirtatious and sexual comments, or touching care home staff in a sexual way. Helen focused on their body expressions and came to the conclusion that whatever desires the older persons had at that moment in time, made them appear to be experiencing pleasure:

...he's just got a wonderful kind of smile on him when he is sexual and he says it kind of cheekily... he sometimes plays with himself and very often he kind of looks you up and down and smiles with this great big grin on his face and you can tell he is experiencing something strong, he just can't communicate exactly what...he obviously still has that desire there, we just ignore that part.

Helen also described a story where a person living with dementia in the care home was wrongly accused of expressing themselves sexually and was labelled as 'perverted'. A gentleman in the nursing home removed his trousers and underwear in the lounge, in front of other residents and staff members. The care staff tried to assist him to pull his trousers, but he refused. He then started touching himself and carers assumed he was attempting to masturbate. Helen realised that due to urinary incontinence his underwear and trousers were slightly wet, which was the reason he did not want to put on wet trousers:

*There wasn't anything sexual in it, but he just didn't want to put them on, because they were wet. So, why would I then continue to force someone to put wet trousers on and walk him through the lounge, just because we think it's not right, him **not having trousers on**? So, I took them off, ehm... put his shoes back on and we put fresh clothes back on. He didn't see anything wrong with that...**but he was half naked in the lounge which caused a stir.** He didn't want to put wet trousers on which, makes sense and ehm... I thought well I agree, but others didn't see that.*

Helen always believed the right thing to do for older persons living in care home was to cover their bodies up and preserve dignity, especially breasts and genitals. Older persons who liked sleeping naked would initially be encouraged to wear night wear of some description, but then staff would allow residents to sleep naked. Helen believes that this is because nakedness can be viewed as bad care and/or neglect:

*Many nurses and carers, I think, think that **not dressing them is neglect, exposing their bodies isn't seen as good practice, but just let them lie naked**, it's not that... well his room is warm, it's not that we are neglecting him in another way, because it would be neglecting and being harmful towards him if we forced him to do something that he did not want to do. It's not just **being naked**, if somebody also wants to **masturbate** in his room that is fine, because that happens as well and that is okay, and that is acceptable.*

Spatiality

Space was present when Helen was discussing the concept of privacy in the nursing home. For Helen, the communal areas such as lounges, hallways, the conservatory etc. needs to be treated as if they were public spaces and need to adhere to normal social etiquette. The lounge is not viewed as a lounge in someone's home where it is their private space and they can do as they please:

*When we [nursing and care staff] **are in the lounge, what we see is the norm. You are in a public space** and you've got to keep your clothes on, you've got to do this, you've got to do that and what is socially acceptable. I wouldn't walk through there with just my knickers on, I would be mortified, but... people with dementia might not see that, they get a feeling, they respond to it, or they **think they are in a lounge where for all their life it has been a private space and now suddenly sharing it with 6-7 other people at one time...***

The Essence of Responding to Sexual Expression for Helen

For Helen, sexual expression was an aspect of dementia care that needed much improvement on the future. She considered sexual expression an important part of a person's life, that provides them with joy and pleasure. Yet, nurses and carers automatically assume older persons do not have sexual feelings. The body and nakedness often provided nurses with challenges, as there are often blurred lines between non-sexual bodily expressions and sexual expressions. Helen's assumption that nakedness is often perceived as neglect and poor care, was a barrier for sexual expression.

David

David is a care assistant who works in the nursing home. He started working in the home straight after he finished high school and has been doing so for just over a year. He was quiet when I first met him. When I engaged in some small talk with him, he would usually respond with his strong west of Scotland accent, a one worded answer. David was curious about who I was and what the purpose of my regular visits was. I spent a lot of time with David informally. I often helped him set up the dining room for lunch and make teas and coffees for the resident's during mid-morning. While we were working, we would discuss Scottish football and went into a mini verbal battle on who supported the best team. He engaged in conversations with many of the residents about football and the latest scores. He often would walk with some older gentleman into the football reminiscing room and listen to the gentleman tell him stories about the history of Scottish football and the matches that the residents attended.

David would ensure that everyone who wanted a daily newspaper in the house he was working in, received one. It was usually the men who wanted a newspaper to read the sports pages. In one of the houses, there was a group of three gentleman who would sit in the lounge mid-morning and read their paper. David would often sit with them reading alongside them and engage in conversations with them. I heard them speak about football, rugby, golf, and snooker. David said that he

enjoys spending this with the gentleman as it reminded him of spending a Sunday morning with his grandfather.

Corporeality

The body was featured in David's conversation when he was speaking about sexual desires. He never thought that older persons had any sexual desire or drive, but when he thought about it deeper, he believed that a sexual desire is human nature:

*I do believe **sex is a human desire** and sex drive is important but I never thought that they [older persons] would **have a sex drive**... I never thought about it, but I just assumed that you don't get a sexual desires when your older, but [laughs] clearly you do...**it is part of human nature** isn't it?*

Relationality

David reflected on older persons living with dementia having intimate relationships with one another. He believed it would be much easier to have a conversation with a couple living with dementia about their relationship if they were married. Marriage was a comfortable concept when thinking about relationships between two residents living in the care home:

*I think **if they weren't husband and wife it would be weird** and... well can they do anything if they are not married? I'm not sure... **its fine with married couples.***

David he spoke of needing support from his colleagues, especially the more experienced members of the nursing and care team when responding to sexual expression. He relied on his colleagues to help him whenever a scenario of sexual expression occurred in the nursing home:

*I would need to go and **tell someone senior** and **get support from them.***

David initially told me that the views and the perceptions that staff have of the older persons who express themselves in a sexual way do not change or their opinion of them does not fall. However, David said that the staff become more

wary of the residents who may touch other staff in what is considered inappropriate ways:

We don't change or opinion of anyone because of it, we know the one's where there is a risk of them touching someone, but... we just know like to keep our distance in case he or she touches...

Spatiality

Space was mentioned by David in connection to the location where sexual expression occurred within the care home environment. There was a clear distinction between the shared spaces with the care home, and the private areas older persons have in the care home. If someone started expressing themselves in a public place, such as the care home lounges, garden area or corridors, then David's first response would be to encourage the person to move into their bedroom or bathroom:

Well if something started happening in a public place, well that that's not right... so I would take the person to the bedroom or bathroom, but I don't know how to deal with it... If they are in private and they are not harming anyone then fair enough...

Temporality

Temporality was visible when David was talking about the lives of older persons and how they lived their lives prior to moving into a care home. Care staff spend a lot of time getting to know important aspects of the resident's life, such as their occupation, favourite pastimes and interests, important relationships, but David never considered the sexual and intimate aspects of their lives:

Well they would have been sexual and close to partners in their past, so why not now? I really have never thought about that aspect of their past, you just think about their jobs, their families and favourite hobbies kind of thing...

The Essence of Responding to Sexual Expression for David

For David, sexual expression is a human desire, which is forgotten in older persons living with dementia. Responding to sexual expression in persons living with dementia is an uncertain aspect of dementia care, which David would need help and support. There is a safety zone when thinking about supporting a married couple fulfil their intimate wishes. Generally, sexual expression is an aspect of someone's life which is forgotten about when they move into a nursing home.

Catherine

Catherine works as a carer in the home. She grew up in the vicinity, married a 'local chap' and raised her children in the same town. Many of the residents grew up and lived in the same part of Scotland and brought that specific culture and way of life into the home. Living in the same area as many of the older persons, created a connection and a bond between Catherine and the residents. I would often sit with Catherine and one or two of the older persons living in the care home and they would be reminiscing about what local school they both went too, their favourite outdoors area, some of the unique shops and cafés and what one of the many pubs in the town was their local.

One afternoon I saw that Catherine spent at least two hours with three older persons perusing at old photographs of the town. I could see the smiles on the faces of the residents. Catherine said she enjoyed hearing the life stories of the older persons she was speaking too, and it evoked a lot of memories for her too. Catherine had a cheerful personality, especially when reminiscing with the residents. There was a lot of laughter coming from the table where they were sitting. She mentioned that she could spend all day listening to their stories as she would imagine that is what her mother and father would have experiences, and some of it she experiences too. Catherine also knew some of the residents before the moved into the care home. I heard her say comments like, 'I remember when me and my mum bumped into you at the shop...', or 'I heard you made the best homemade Victoria sponge cake in the street'. Catherine wanted to keep the older persons local memories as alive and vivid as possible.

Corporeality

Catherine shared an experience she had when an older gentleman expressed his sexuality. The body played an important role in this scenario as the older gentleman would sometimes expose his body in the lounge of the care home. For Catherine, having the flesh on display would be considered as a form of sexual expression and viewed as inappropriate for the home:

*He would sometimes **expose himself** in the lounge. Like maybe undo his trousers and **touch his groin area**, like you would **see certain body parts**... We would just go and put a wee blanket over him, you **know cover him up** until he calms down a wee bit or wanted to go to his room...*

The body was also spoken about in terms of Catherine being touched by an older person with dementia who she was providing personal care too. She told me about another gentleman who would often express himself sexually when he was getting assisted with showering, again another scenario where body and flesh is exposed. This gentleman would often touch Catherine's body as well as his own:

*...he would be quite sexual when you **were showering him** and he would say things to you, you know like sexual things to you, but he would be fun with you too, it was his sense of humour... but sometimes you would get him showered, **he would touch himself** but also **his hands would go everywhere you know**, like on me, **on my bum, my breasts**... A few residents are **very touchy feely** like that...*

Catherine responded to the gentleman by saying that she is married to another man and he was not to touch her in a sexual way. She told me that it was the easiest way to de-escalate the situation and they would usually stop touching her and themselves. Catherine started to think about her thoughts on what lies beneath such expressions:

*Maybe **deep down** they would like to continue an intimate aspect of their life, you know **deep down** that is probably what they are asking, and it's just their personality on whether they say it jokingly, you know what I mean, **or***

*express it in a certain way, there could be a **genuine desire** behind it...we don't know exactly what **they are feeling**, like they could be lonely and that's only natural and of course **they have feelings as well, even sexual feelings.***

Relationality

Catherine mentioned how much the staff involve the families and felt it is important to keep the relatives of the resident's happy as well as the resident's themselves. Catherine imagined that relatives would generally be unhappy about staff supporting someone's sexuality:

*It might **bother the families, we have to speak to the families...** you have got to think about well **would the families be happy about us speaking about their loved ones sexuality** when they have dementia or how they may like to continue an intimate life you know. You know it's a hard one because if they [older person with dementia] were out and about in their own houses they would just do what they wanted to do and this care home is their own home, but **family perspectives and opinions are a big thing in here.***

Catherine then focused on relationship between the older persons living with dementia and the care staff. She believed that the staff in the nursing home should respect the different values and beliefs that every individual holds, including person's sexuality:

*Whatever personal life they like or want, **staff should not make a judgments** about their values, should we? **We shouldn't judge people anyone in here** and see if they are happy, that is the main thing. As long as they are safe, comfortable and happy that the main thing, but **we are not here to judge...** it's a normal part of life, **who are we to stop them** as long as they are happy...*

Catherine believes that giving people the chance to have discussions about their sexuality and sexual expression, would provide staff a fuller and deeper

understanding about a person's life. It would also help Catherine understand the needs the person had and would ultimately help her provide better individualised care for them:

I have never thought to have a discussion with them, you know, ask them what they are thinking... but why can't we ask them what they want in life...some will be willing and wanting to speak to about it, they would probably tell you so much and you would find out a lot about the person that would help you care for them...

Spatiality

When persons with dementia move out of their own private home and into the nursing home, Catherine makes an effort to find out as much about that person as they possibly can, such as their daily routine, what they like to eat, what hobbies they have etc. She made a point that sexuality does not get discussed. Catherine pondered whether at the point where the persons living with dementia are moving into the care home would be an opportunity for any discussions around sexual expression to be had:

*When **someone is moving into the home** you know, you discuss what they like to eat, to wear, their normal routine, but we don't talk about sexuality, it might give you the opportunity to talk about what their needs and preferences, or how they express their sexuality right from the word go, and it becomes normal... but we don't do that.*

Temporality

Time was present for Catherine's in terms of how sexuality was viewed in different times and in previous generations. She felt that people growing up during a time where they were more conservative when it came to matters around sex contributes to not discussing sexual expression in nursing homes:

We would never talk about it even in my younger time, and sometimes when you hear maybe like one of the residents like talking that way or in a dirty or in a sexual way, you will get the odd resident who is like 'that's

*terrible, that's disgusting'. So, it depends I think on some people **who have been brought up perhaps in a stricter way**, other people may be more relaxed with it you know what I mean, and everybody is different, everybody has a different personality don't they? So, they have... they are different yeah so they are...**Times were so different when our residents were younger.***

The Essence of Responding to Sexual Expression for Catherine

For Catherine, a person's sexuality is often left behind when they move into a nursing home and any 'issues' around sexual expression gets swept under the carpet. Sexual expression is generally when persons with dementia touch their own bodies, or the caregiver's bodies along with saying sexual comments or suggestions. Catherine believes there is a genuine sexual and/or intimate desire behind each expression, but sexual expression is not a topic spoken about in the home. Catherine thought that older traditions around sex and intimacy was thought to influence the assumption that older persons do not want to talk about sexual expression.

Emily

Emily was a senior carer in the home and had been for several years. She was a very open person and confidence oozed out of her. She would often be going about her daily work, sharing the current stories of the current affairs of her life with whoever she was working with. She did not seem to tone down what she was saying when I was around, even the first day I met Emily and was working with her. Right away she agreed to be observed and to speak to me for the research, almost without even blinking. 'Yeah, I'm totally up for that', she said to me reading over the participant information sheet.

Emily was very witty and any encounter I had with, there was always a comical drama attached to Emily's life. I imagined Emily would be great on stage. Whenever she told a story, she would not just tell the story, she would act it out. She changed character with every person she was speaking of. Her language was dramatic, and

she held everyone's attention. Many of the older persons living in the home loved her sense of humour and presence. Emily was not afraid to make a fool of herself and 'goof around', whether that was an attempt at dancing or singing while she went about her work. The older persons living in the care home would react positively to Emily's theatrics and would laugh along with her.

Relationality

Relationships were important for Emily. When talking about persons living with dementia having intimate relationships, Emily believed marriage was an important enabler for such relationships to continue to take place. Marriage placed a safety net around the whole issue of sexual expression and being intimate with another person:

*If you have **a married couple** come in who are very much **set in their ways**, and they understand their ways, who are we to stand in the middle of it, or change them or interrupt their routine, **they can see each other** and do what they want **in each other's bedrooms**, that is fine...*

If a new relationship between residents developed any further than friendship, Emily believed some form of action would need to take place such as encouraging persons to remain as friends. She also believed families and POAs would need to be involved as they make decisions for persons with dementia:

*There would have to be **some discussion with the family** and maybe bring the manager in to deal with it, **the families are there to make decisions** for the dementia resident, so **you need to ask them**..*

Emily was reflecting on scenario's where a gentleman who was living in the home would make sexual comments towards her. Emily said that the best way for her to respond to the situation was and to maintain a positive relationship between the gentleman and herself, was to respond with a cheeky or witty comment:

***You need to have some banter with the residents** when they say certain things, personally I think that is the best way as **they then have a laugh**, because if you didn't they would respond in an angry way...*

Corporeality

When Emily was speaking about using humour to respond to sexual expression, she thought about the consequences of not responding in a humorous way. Emily considered the emotions and feelings of the person living with dementia and felt that by reacting negatively to his sexual expression it would evoke feelings of reject, anger and sadness in the gentleman:

*So, **he would be like aggressive and he would be like angry and upset** if you just told him to stop it, as if he was just **turned down and rejected**. So, you just need to be funny with it and he is fine with that, he **doesn't seem to get upset** with that...*

Emily found that when a person with dementia would expose their naked body, usually their genitals, she felt that this caused her and the majority of her colleagues a challenge and presented her with an issue she had to 'deal with'. She thought of another gentleman who used to expose his body and Emily considered that this was because the gentleman was wanting to masturbate:

*He would be **on show**, you know **have it [the gentleman's genitals] out and on show** for everyone to see, he would often try and masturbate but because he has dementia he doesn't know what he is doing, so he just needs led to his room and that's what I would do to deal with it...*

Spatiality

If sexual expression occurred, Emily believed that persons living with dementia needed to be in their own private space. If they were not in privacy, Emily would direct them to their own bedrooms or a bathroom in the home:

*As long as it's in **their own private space**, people can do what they like... If dementia residents are expressing themselves or displaying themselves*

*around other residents then I would take them to **their room or the nearest bathroom...***

Emily spoke about space in terms of living in a residential setting compared to living in the home. She felt that a nursing home was not the environment for sexual expression to be a normal part of life for a person with dementia. For Emily, being in control of your sexual lives and sexual expression meant that a person should be living in their own private home:

*Well I don't think people with dementia can make decisions about their sexual lives and sexuality and stuff you know. If that's the case **then they should be living in their own homes** and making their own decisions, **they shouldn't be in here** if they can make their own decisions and stuff... **It's just not the place for sexual expression** and things like that...*

Temporality

Time for Emily was present when she was discussing the frequency of sexual expression. The more someone made sexual comments, or exposed themselves within a certain period of time, the more of an issue it became for Emily. The amount of times sexual expression occurred was determinant that sexual expression would be included in an older person's care plan:

*This gentleman you know, he only says things or does things a **couple times a week**, so it won't be in his care plan. He doesn't do it often enough for it to become a major issue and we need a behavioural plan or anything like that...*

The Essence of Responding to Sexual Expression for Emily

For Emily, a nursing home for persons living with dementia was not considered appropriate environment for sexual expression. Sexual expression in persons with dementia was when a person's body, especially their genitals, were exposed and if a person was masturbating. Private spaces in the nursing home were essential to 'deal with' sexual expression. Families of persons with dementia were considered essential to talk to if sexual expression became an issue. Sadness and anger often

ensued if a staff member stopped sexual expression. Having meaningful sexual relationships was considered important part of sexual expression but was only accepted in the concept of marriage.

Liz

Liz was a woman who was full of energy and gusto. She had a high level of enthusiasm on a daily basis. It was infectious. I felt lively and energetic myself and enjoyed being in her presence. She worked in the nursing home as a care assistant and voiced her love for the job on a regular basis. She told me that she could not see herself not working in care and looking after older persons living with dementia.

She had taken on many different jobs over the years but was her happiest as a stay-at-home mother. She is a mum of two, both who are in their twenties now and was extremely proud of her children and their achievements. She would speak about them with full motherly pride glowing from her. She would have an uncontrollable smile when she was talking about her family. She said that she had a very close family unit and always has had. When her children were grown up teenagers, and needed much less care and attention, she wanted to continue making a difference to people and providing care in some shape or form. After a brief job working in a nursery, a job became available in this nursing home, and she wanted to give something back to the older generation of the community. Liz saw her job as a carer as something more than to pay her bills and mortgage; it was an opportunity to make a difference to many people. Liz would approach everyone with a smile and in a cheery manner. When a resident was feeling a little upset or not having a good day, Liz would always try and do her best to make them much happier, by sharing jokes and giving them a comforting hug. She wanted to make everyone smile and feel good about themselves.

Relationality

Liz shared an experience she had where two residents formed a relationship and would be seen to be cuddling each other and wanting to spend time in each other's room. Liz compared the people that she provides care for with how she views her

mother and father. She recognised this being a challenge when thinking of sexual expression as Liz would never think about her mother or father as persons with sexual and/or intimate needs:

*Looking at it from **my point of view and thinking about my mother, or even my father** you know, if one of them had to go into a care home and they saw intimate interests in another person, I ehm... would be like, **that is totally not for them...** but I suppose I wouldn't be thinking about **her feelings**. You know, **you don't want to think about your mum or dad as you know sexual people**, you never have done and **that is how you think of people with dementia...***

Relationships with colleagues was also important for Liz when thinking about scenarios of sexual expression. When Liz first started working in the nursing home, she needed guidance from experienced staff on how to respond to persons who may say sexual comments of touch the care staff in sexual ways:

*When I first started working here, **I totally needed the guidance from colleagues**. **The colleagues who I buddied up with** would warn me about the residents who were sexually explicit or who might touch you... **yeah the support from colleagues helps you to deal with it.***

Liz said that using humour was an effective way for her to respond to sexual expression. This was because Liz felt that she knows the residents who enjoys the banter relationship with the staff. Liz believes that the relationship that has been created through herself and the person with dementia allows her to gauge her response to sexual expression in persons living with dementia:

*I mean I think **we know our residents so well and we do know that we can humour him**. Sometimes he would say certain sexual things and **I would reply in a funny way** and he would be chuckling and laughing away, you know it completely diffused the situation and he wouldn't mention it again, he just had a laugh. **It really is about how well you know the resident and***

whether you react with a funny comment, you use distraction, or you just ignore...

Corporeality

Liz shared story about the married couple that was living in the nursing home. Liz felt that intimacy was expressed when the husband and wife would be seen to be touching each other's bodies and displaying signs of affection, such as handholding, kissing and cuddling. For Liz intimacy provides older persons with positive emotions is a human need:

*They did sit and **hold hands**, and they also liked a wee **kiss and cuddle**. I remember a couple times we would find them lying on top of each other's bed, **in each other's arms**, but not sure if there was every any, you know, **full intercourse, just a cuddle**, which is a lovely form of affection, **makes people feel good** you know... it is a **human need and is very emotive**.*

Liz believed that if a person expressed themselves sexually, then that person has an underlying need and desire that they are experiencing. She compared having a sexual need is no different than any other desires that humans have, like hunger is a need to food and nutrition:

*I do think many of the people we look after **have sexual feelings**, the gentlemen I have spoken about, **I do think they have a sexual need**. If they ask for something, I do think there has been something that **has sparked that feeling** for him, so yeah... **it is definitely a need or a desire**, just like being hungry is a need.*

Liz felt that some older persons enjoyed showing off their body and wanting to feel attractive or 'sexy'. The example that Liz gave was of an older woman who wanted to dress in way that was showing off her physical features. Liz felt it was often laughed at by staff. Liz believed that many people still wanted to feel good about themselves, and cared about how they looked and that was how they wanted to express themselves:

*We have a woman living here who once asked me if she can get a dress you know, **one that shows off her cleavage so her breasts are out and one that has a split up to here** [Liz pointed to the middle of her thigh].. **she wanted to show off her cleavage and feel sexy** you know, **look and feel attractive...** She was going to a dancehall and wanted all the guys to be chasing after her, you know **that made her feel good**, she wanted to **feel like an attractive woman**, but many people laughed at the thought of her wearing a low cut, high split black little number and **showing off her body...***

Spatiality

Space was important for Liz's as was talking about persons living with dementia who expose themselves in the communal areas of the nursing home. Helping the person to move to a private area of the nursing home, e.g. their own bedroom or a bathroom was a common response for Liz when a resident felt the need to remove their clothes:

*...he would start exposing himself you know, sometimes **even in the lounge or sitting at the dinner table**. Well, for other people it isn't a nice thing, **especially at the dinner table**, so we would guide him to **his room or bathroom** and either give him time or sort him out... That needs to be done in the **privacy of their own room**.*

Temporality

Liz feels that how society views sex has changed completely as time has moved on. When she was growing up, sex and romantic relationships were not spoken about widely and it was a very taboo subject. Liz believes these influences certain assumptions that people hold about sex and intimacy in older persons:

*You know when I was growing up, **it was a totally a different time**, we are in a different world now when it comes to sex, I couldn't utter the word in front of my mum and dad and now you see sex everywhere, so you must assume that older people don't want to talk about it, **but times are changing...***

The Essence of Responding to Sexual Expression for Liz

Thinking of persons living with dementia in the same way as your mother or father, or a grandparent, resulted in Liz not considering persons with dementia as sexual persons. Liz feels that previous generational traditions around sex and intimate relationships continues to share how nursing home staff view older persons including those living with dementia. Having a good relationship with residents means Liz responds to sexual expression using humour. For Liz, she needs the support and guidance from her colleagues to respond to sexual expression. A person's sexuality and sexual desires were often expressed through genitals becoming exposed, touching one's own body or wanting to wear clothes that made them feel attractive.

Tanya

Tanya had a very quiet nature and was quite shy with everyone, including her co-workers and the residents who she was providing care for. Tanya considered herself a 'newbie' to care with lots to learn. As a mature woman, she felt that she took longer to pick things up and she needed time to learn new skills and work at a faster pace. Tanya often compared herself with the other carers and nurses. She felt that she was a lot slower than others at completing care tasks. She was much more of a listener than a talker. She was always on the periphery of all the workers' chit-chat. She told me she was happy to sit and absorb everything that was going on. Tanya would not say very much but would laugh along with 'hot topic' of the day. This was usually about weekend adventures that staff had on their days off or analysing the latest celebrity gossip.

Tanya's favourite activity was to offer the older persons with dementia hand massages and to give manicures to the female residents. This would happen in the beauty and relaxation room. Tanya would sit with either one or several residents and listen to whatever the person was sharing. There was peaceful atmosphere. She would put on gentle spa music so the residents could listen to the sound of the ocean in accompaniment with Tibetan bells. She said that she enjoyed taking a couple hours to do a pampering session. Tanya said that even if no one wanted

their nails painted or given a massage, some of the residents would sit in here just wanting to relax in peace and quiet. Tanya joined them when she could. It gave her some time to chill during a hectic twelve-hour shift.

Temporality

Tanya spoke about time in relation to how sex and intimacy was viewed in the past. She feels that different generations may have different perspectives, especially with having discussions about sexual expression. Tanya believed that future generations may be more equipped to respond to sexual expression as she thinks the culture is shifting to becoming more open about sexuality and intimacy:

I think as time goes by and you are coming along the generations, it will become easier to talk about, times were different when I was young and certainly when my parents were young...

Tanya believed older persons living with dementia having need time to be alone when living in a nursing home. She shared a scenario she had when she walked into a bathroom and interrupted an older gentleman who was masturbating. Tanya believes that many people enjoy having alone time and had a right to do what they want when spending time alone. She feels that having time to be alone is a hard thing to have in a nursing home:

So you are respecting that is his private time... You know everyone needs their own time to be alone for whatever reason. Everyone deserves that at least and I suppose it must be difficult to get that in here.

Spatiality

Space was very closely connected to the temporality aspect of Tanya's conversation. She felt that residents deserved their own space just like if it was their own private home out with the nursing home. Tanya spoke about the importance of how much a nursing home is their own space and they deserve to use that space in whatever way they choose:

*The main thing that I have taken from here is that **it is their home**. It's not a hospital environment **it's their home**, and they have **their own private rooms**... I mean we had a wee couple but they had separate rooms... it's a shame your bringing them in and then saying your room is there and your room is there... **They deserve their own space to do what they want**...*

Relationality

Tanya challenged her own assumptions about the relationship she has as a carer with persons living with dementia and how that impacts on the person making their own decisions. She imagined herself in a care home and she would want the staff to help her make own decisions, rather than others to make the decision for her:

*...you are helping me think these things through, because I would have never thought, 'how would I have felt if it was me?' **We should be helping the residents make their own decisions**, we are hear **for support** not to make decisions for them... I would want help making my own decisions, not for someone to make them for me.*

Tanya felt that she had a paternalistic relationship with the older persons she was caring for. She thought how thinking about the resident's similar to her parents shapes her relationship with the older persons living with dementia. She feels that other nursing and care staff view persons with dementia in a similar way:

*...**you do think of residents as your parents or grandparent**... because I do, I would automatically think, '**what would I think if it was my mum or dad?**' I would never have thought about what would I think if it was me? I never thought about that before... I am and I think others are **very paternalistic towards the residents and you do think about a parent or grandparent when you look after older people with dementia**...*

Corporeality

For Tanya, sexual desires were never associated with older persons, including person living with dementia. This was one of the reasons that Tanya felt 'shocked' when she first experienced sexual expression in someone living with dementia:

*I think it's just because we see them as elderly and these sort of things don't happen when you get older, they obviously do now that I think about it and was shocked at a few experiences, **but sexual desires and you know, those feelings do not get associated with the elderly...***

The naked body was present in Tanya's transcript. She said one of the worst experiences was when a gentleman requested a sexual favour from Tanya. One of the reasons she felt this experience was challenging was because he was wearing no clothes at the time. Therefore, his body was fully exposed:

*Once ehm... **it was a gentleman who likes to sleep naked** and I was coming in to help him get showered and he was like, 'come and sit on this' and I was just like 'I don't think so' and I was carrying on just getting his clothes ready, **but I did feel a wee bit threatened because he it was just me and him and he had no clothes on at the time. I did feel a wee bit threatened, I just got his clothes ready and it fizzled out.***

Tanya also spoke about the different views she had about male and female sexuality. She thought that sexual expression was more likely to occur with older gentleman rather than older ladies. She did not associate a high sex drive with women:

*I don't think about **a woman being or having a high sex drive, even younger women....** You just always think it will be the **male.***

The Essence of Responding to Sexual Expression for Tanya

For Tanya, sexual expression was initially a shock, and is now a challenge to deal with. Sexual expression is more surprising coming from an older woman than an older man. If a person is expressing themselves and they are naked, this was more challenging for Tanya. Private time and space are important if a person wants to express themselves in certain ways, but nursing homes do not always accommodate sufficient private time and space. Nurses and carers often make decisions for persons living with dementia, rather than facilitate the person to decide which discourages sexual expression to become part of care.

Mark

Mark is a senior carer working in the nursing home. He is in the process of writing his application to study nursing at university. He told me that he enjoyed his eight-year experience as a carer and wanted to build on his skills and knowledge further and become a registered nurse. Mark would often be the senior carer in charge of one of the houses within the home, with the support of the nurse in charge. He enjoyed being a small team leader and said he would always want to lead by example. Mark wanted more education and qualifications to have more influence on care decisions.

Mark and a couple of other residents sat at a dining table having a cup of tea and playing dominoes. I was invited to join them. We played until someone won five games. It was competitive. The residents wanted to beat the 'young ones'. They did, with flying colours. While we were playing, Mark was being very playful and humorous with the residents. The residents were laughing and giving him sarcastic comments back. Mark said he wished he said that one of the disadvantages of being the person in charge of the house was that he had less time to socialise and participate in activities like what we were doing at the time of this conversation. He was frustrated about much time he must spend doing paperwork. Mark would rarely be seen in the office. He would regularly bring out his paperwork and sit at the dining table to write in the plans or progressive notes. Mark would sit in the dining room while the residents were socialising or relaxing in the lounge. He said he did this so he could be with the residents in some capacity. He could be on the edge of the chit-chat, be there with the residents in the same open space. He was frustrated that he had to balance being involved in the conversation with having to concentrate to complete all the paperwork he needed to before he could go home.

Corporeality

Mark believed that every person has to some extent sexual and intimate feelings and thought that having a diagnosis of dementia would not suddenly remove a person's sexual feelings. He saw sexual needs and feelings that are something that forms each and everyone's unique identity:

*I mean what if people were **sexually active** right up until coming into here, you know I think just because they get dementia **doesn't mean that sexual feelings or romantic feelings don't go away**, they won't just suddenly disappear... **we all have sexual feelings to some extent, it's part of who you are.***

Mark was sharing a care experience he had when a gentleman who lived in the care home would express himself sexually. Mark thought that by not including a resident's sexual expression or intimacy needs within the care he provides, he was in some respect taking away a part of that person's identity:

*You know, now that I think of it, by not supporting like you know, **his sexual needs or feelings**, or not including sexuality into his care, **you could be taking away some of his identity...***

Mark spoke about the importance of being physically close to another person is important for overall wellbeing. He said cuddling up with his partner was important to him. And how he would experience feelings of sadness if he could no longer be intimate with his partner again:

*I mean **being physically close to someone is important** for many people, even at night you know **just having a cuddle, that feeling that someone is cuddling into you and you can feel their body against yours**, imagine being used to that for so many years and then to have that taken away... **aye I wouldn't be happy with that... that would make me upset.***

The body was also highlighted by Mark when he was describing a common form of sexual expression. He cares for a couple of gentlemen who would frequently touch the female care staff's bodies. When this occurred, Mark would assist the gentleman with their care in case the female member of staff felt uncomfortable:

*There have been a couple of scenarios like with male residents **touching female staff**, but each time they haven't made a big issue of it, like the resident **who was touching a carers breasts and another one was rubbing***

a female carer's bum and they just carried on with care... sometimes if it happened a lot I would go in and assist the person with their care so that the female carer wouldn't be uncomfortable.

Relationality

Mark focused on the relationship between himself and the residents, especially when someone expresses themselves. He thought about scenarios when residents masturbate in the lounge or other communal areas of the home. Mark shared with me that the main responses are usually to distract the person or ignore the expression all together. He then wondered if sexual expression should not be ignored, but nursing and care staff should see it as an opportunity to discover more about how the person is feeling:

We would just try and distract him** you know, because you could see some carers or other residents getting disturbed by it, so yeah **you would do your best to distract him or ignore it**, but he isn't doing anything wrong... Maybe that is **the time and opportunity to have a private chat with him or any other resident about their feelings**, but I wouldn't know how too or what to say. We don't know how they are really feeling, but we should, **I just wouldn't know how to engage with it, without making them feel embarrassed or uncomfortable.

Mark spoke about the relationship between the person living with dementia and their closest family. He thought that families would struggle with concept that their loved one might be expressing sexual and intimate needs. He believed that for sexual expression and sexuality to be a normal part of nursing care and nursing home culture, families/power of attorney's as well as care staff needed awareness so they know that sexual expression is important for many persons including older persons living with dementia:

*There's also **the families** you know, **relationships** and intimacy aren't on the nurses and carers radar, and **it certainly won't be on the families radar**, you know, maybe their mum or dad has been diagnosed with dementia and*

*no one likes to think about their mum or dad, or whatever the relation is, no one wants to think of them in that way, but everyone had a private life, but it's forgotten about... It would be great for the **relatives and families to know that it is still part of the person's life** and it doesn't need to stop just because a loved one has dementia.*

Spatiality

Space was spoken about in terms of the physical environment of the nursing home. For Mark, the care home environment is not a space for people to have privacy and for couples to be together and have the opportunity for intimacy. Mark thought that the environment was giving off a poor message about sexual expression and relationships.

*It is maybe even the fact that **in here it is single rooms and single beds**, so like **they are sleeping in a bedroom by themselves and being told that this isn't an environment for couples to be together**, either couples who have been together for a long time or newly formed couples.*

Temporality

Mark as he believed that persons living in the nursing home deserved their own private time. Mark feels that experiencing your own private time is challenging and even though a person may be alone in their room, they will often be disturbed, and their private time can stop very quickly and unexpectedly:

*Everyone deserves **their own private time**, but even in here, **they must feel that they are never alone**. When they are in their own room, they can have carers coming in and out, **their alone time could easily be disturbed and it often does get disturbed**, not through anything other than carers and nurses trying to do their job.*

The Essence of Responding to Sexual Expression for Mark

For Mark, having sexual feelings and being able to express them is part of a person's identity and not acknowledging that part of someone's identity is considered poor care. Mark felt uncertain and unequipped on how to care for that part of someone's

life in a respected and professional manner. Sexual expression was considered as persons with dementia masturbating, exposing themselves or touching caregivers' bodies. Ignoring the expression or distracting the person was the best approach. Mark believed that physical body contact with a partner is considered an important part of life that should not have to end by moving into a nursing home. Mark felt that families and representatives of the person with dementia need to understand the importance of sexual expression.

Erin

Erin took me on my first orientation tour of the home. During the tour Erin was approached by many of the residents who we met along the way. They were all very familiar with Erin and she was met with a smile with the residents we met along the way. Some immediately took her hand. Others smiled and waved at Erin. She was a good conversationalist. Erin would talk to everyone who walked by. She would always ask how my day had gone and if I had any issues or came across any problems. Whenever she needed to do her office work her door would be left open. Residents would walk in and out of her office as they pleased, and Erin would always engage in a conversation with them. Some residents would sit with Erin in the office and she would give them a refreshing drink. Some of the older persons living in the home would like to see if Erin needed help with anything. Others just like to sit in the office area and chat away with Erin. One gentleman liked to observe Erin at work. Erin would involve him in what she was doing if she could. The gentleman found enjoyment out of believing that he was working alongside her. Erin would show him how to work the shredder, photocopier and he would assist her. He also would regularly sort out her files in alphabetical order. She told me that the gentleman looked disappointed if he came in and they were still in alphabetical order. So, Erin would purposefully scramble them as she knew that the gentleman would be in a day or two later to check if the folders were neat.

Spatiality

Erin felt that education needed to create a space for all nurses to have the opportunity to learn about sexual expression in the context of older persons and

persons living with dementia. She believed that more education would encourage critical self-reflection so that they can become aware of their own values around sexual expression and provide the best holistic care for the older person living with dementia:

*Well there is so much done on mandatory training, and it's all great subjects so it is, and important, but **no education around things that matter to the person with dementia like sexuality or relationships...** No education. **We need space to talk about this and learn about this.** We need education and reflection. Because I think until you delve into your own feelings and beliefs and stuff around something, you don't actually realise how much they are impacting on possibly the care you give. But I do think **you need to be given the space to do so...***

Corporeality

Erin was describing some of the most challenging aspects of sexual expression, the body being exposed. When flesh could be seen, in particular, genitals and breasts, the usual response would be to try and cover the person up or to assist them to their room so they could continue to express themselves in a way that maintained their dignity and did not upset others:

*If **someone was touching themselves** you know, or **they were on show** then it would be very difficult for the staff to deal with, **especially if it was breasts or genitals.** They keep asking me what to do, or they would just try and cover that person up or take them to their room...*

Erin spoke about sexual expression and gender. There was different perceptions and reactions from staff were imposed on men and women. She used masturbation as an example and said people's reactions were totally different. Erin believed that older females are even more forgotten about when it comes to sexuality and it can be more surprising when a female expresses themselves in a sexual way:

*It is really interesting, I have cared for **men and women who express their sexuality and enjoy to masturbate.** It's funny to see the difference, well, not*

*funny just ehm... surprising. Like with the **man it was obvious that he wanted to masturbate**, and he was viewed as being, you know, an old dirty man. Whereas, with the woman I looked after, **perhaps because of the female anatomy**, but initially people thought **she was irritated down below**, masturbation never came into anyone's mind, but there was one time in the bath you could see **she was pleasuring herself and really enjoying it**. Everyone was completely shocked... I think there is **definitely still a gender separation around sex**.*

When two individuals living in the nursing home form a relationship with one another, they express their connection through some physical acts and touching each other's bodies. She believed that these signs of affection and close touching stirred positive feelings and emotions for the residents. Erin said some gestures and touching was more acceptable than others:

*Many residents get so happy when they form a bond with someone in here. Those **kisses and cuddles are so important to them and the feelings they get from it is invaluable** you know, but **it was gentle forms of touching that is seen as acceptable**, any more contact, for example, we had a relationship that was formed and he would **cuddle her and touch her breasts, her hand would be on his thigh, like stroking his thigh** and that was seen as totally unacceptable...*

Relationality

Relationality was present through Erin's transcript in respect of when two older persons living with dementia have formed a new relationship. Erin saw value in everyone having a meaningful relationship, one that provides people with connection and intimacy, including with older persons living with dementia:

*The couple in themselves were very happy with their **new relationships** and its **true relationships** provide you with **connection and intimacy**, and that is so important. I would say even more so when you get older in some ways*

and for the residents with dementia. We all need **that someone** that we can lie **beside**, cuddle and share things with.

Erin spoke about the relationship between the persons with dementia and their relatives/POAs. Erin feels families influence newly formed relationships negatively can have impact on the resident's wellbeing. The relationship between the families and caregivers were also prevalent in Erin's reflection:

Our challenge would be the relatives, the POA's, they can sometimes be a barrier to you providing what we believe is the right care. Like **with the couple** who both had dementia, but both had the capacity to give consent, **the families were okay about their newly formed relationship**, they would go on dates, hold hands and kiss and things. However, they were found having sex and **the families put a stop to it as it got to a level where they thought it wasn't acceptable, and they blamed the staff for allowing it to happen and adult protection got involved**. They were separated, they weren't allowed to see each other, and she died really quickly after. I genuinely believe she died of loneliness...

Temporality

The temporality element in Erin's conversation in the context of how people are changing their perception of sex and intimacy as years and generations go by. Erin hoped that as younger generations get older and times change further, then she hopes that sex and intimacy becomes a normal part of a nursing home culture:

*I hope that this area of care **improves in time**. You know, we have come a long way with so many aspects of care but we badly fail with this.*

Discussions around sex or sexuality are changing as time goes by, it is about time we start addressing the intimacy and sexual needs of older persons, and those living with dementia.

The Essence of Responding to Sexual Expression for Erin

For Erin, sexual expression in older persons living with dementia is a taboo subject which needs to be tackled. Educational and learning spaces is needed for nursing

homes to understand the importance of sexual expression in persons with dementia. The challenges mainly occur when persons masturbate or expose their bodies. Sexual expression by males and females is also viewed differently by nursing and care staff. There was recognition that intimate relationships are important for many persons and intimate and/or sexual contact provides many with positive feelings and connection. For Erin, families, and representatives of persons with dementia provide barriers for care staff to facilitate and support sexual expression.

A Synthesis of the Essence of Sexual Expression as Experienced by the Nursing Team

Up to this point, I have presented the nursing team participant's descriptions which has included a short narrative about the individual, followed by their accounts of sexual expression as presented through the four existentials. Following the participant's descriptions, I created a summary of their descriptions to capture the essence of their understanding of sexual expression in persons living with dementia lived out in a nursing home setting for each nursing team participant. My next step was to synthesise the essences together to come closer to understand further the phenomenon of sexual expression in persons living with dementia as experienced by the nursing team.

By synthesising the participant's descriptions and essences there was a risk that my interpretations could become too removed from the participant's meaning. I did not want my interpretations to become a shell of the participant's experiences. The aim in the next step of the analysis was to describe the phenomenon of sexual expression in persons living with dementia as experienced by the nurses, and for the description to connect with the original transcripts. Therefore, to synthesis the participant's descriptions and capture the overall essence of sexual expression in persons living with dementia as understood by the nursing team, I worked with two processes. The first process was that I read and re-read my interpretation of their experiences, which is written above, along with reading their individual essence summary. While I was doing this, I was extracting key words and phrases, or gems

that felt meaningful and shouted out at me. I wrote the key phrases on a separate piece of paper. I had a large list of words and phrases that came from the participants descriptions. This process is what van Manen (2014, p. 320) the selective reading approach where we listen to or read a text several times and ask, 'What statement(s) or phrases(s) seem particularly essential or revealing about the phenomenon or experience being described?' I then welded through the different phrases and connected phrases that related and had a strong connection to each other. At this point, I had different clusters or 'themes and insights'. I then attempted to write a phrase that captured the meaning of each theme. I did not want each gem that I took out from the description not to be connected by the phrase I used. I went back to each phrase, or gem, that I selected and tested it connection with the overarching phrase. This process was circular and time-consuming, yet important to me as I wanted every participant's contribution to this research to be felt within the overall essences.

My next process was to go back to the original transcripts for each participant and do the same thing as I had done with the phenomenological text that I had written. I read and re-read the transcripts and extracted the gems of the participant's experiences and captured them all on a separate piece of paper. After reading through all the transcripts, I had a similar busy and very messy piece of paper covered in words and phrases. After linking phrases with the same or similar meanings, I was left again with clusters of phrases. Similar as the process above, I creased a summary phrase that captured the theme of each cluster.

Once I had two lists of elements that described the essence of the nursing teams understanding of sexual expression in persons living with dementia, one via my phenomenological descriptions and the second through the original transcripts, I compared them both. I had them both side by side studied them in detail. The two lists were very similar. A couple of words differed, and the order was different, but the meanings were the same. I also showed the lists to my supervisors who believed the lists emerged from the same source. This gave me confidence that through my

synthesis of the participant's experiences, I as best as possible, stayed true to the participant's meaning.

From the participant's descriptions of their lived experience, the following nine essences create the essence of sexual expression in persons living with dementia lived out in a care home setting for each nursing team participant:

- An attribute of being a person forgotten about or not considered important for flourishing.
- A human desire which is not associated with older persons living with dementia.
- Considered as a private aspect of a [younger] person's life.
- A dynamic spectrum of various expressions, with some being acceptable and others unacceptable.
- A challenging aspect of dementia care giving which evokes feelings of embarrassment, uncomfortableness and/or shock.
- Easier to ignore, desexualise, use distraction techniques or approach with humour.
- Uncertainty on how to be person-centred and what is the right thing to do as a team.
- Unsure of any meaning behind the expression and how the person is feeling.
- Anxiety around the perspectives and opinions of families/legal representatives and the primary desire to please them.

I have created a pathway to get close and to almost touch the phenomenon of sexual expression in persons living with dementia as experienced by the nursing team. However, I recognise that not all the participants experienced all nine essences at any one time and some element will ring truer for some persons than others.

The Phenomenon and Lived Experiences of Sexual Expression in Person Living with Dementia as Experienced by the Nursing Team

Through a process of continuously engaging with the essences and understanding of sexual expression in persons living with dementia for the nursing team, returning to the phenomenological descriptions and the original transcripts, I created definitions of the phenomenon of sexual expression in persons living with dementia as experienced by nurses. I shared potential descriptions with others such as my supervisors, fellow PhD candidates and the nursing home manager. I received feedback on their thoughts and how relatable the definitions were to them, which helped me create two definitions. The first was to describe the phenomenon of what is sexual expression in persons living with dementia as experienced by nurses. The second definition describes the lived experience of caring for persons living with dementia who express their sexuality.

I propose the phenomena of sexual expression in persons living with dementia as experienced by the nurses to be:

A dynamic spectrum of various acceptable and unacceptable expressions, the meaning of which is predetermined by the nurses, and is grounded in perceiving the ageing body as desexualised.

The lived experience of caring for persons living with dementia in a nursing home who express their sexuality is:

A challenging and uncertain element of dementia care, which is often forgotten about, evokes feelings of discomfort and anxiety, and is easier to ignore or respond using distraction or humour.

So far in this chapter, I have focused on the nursing team's lived experiences of caring for persons living with dementia who express themselves sexually. From looking at their transcripts and field notes through the lens of four lived existentials, I have shared their story of what it means to them to care for persons living with dementia and to respond to sexual expression. I have then summarised the essence of responding to sexual expression for each nursing team participant, before bringing them together in synthesis and creating nine elements which I suggest

capture the essence of sexual expression in persons living with dementia as experienced by nurses. This has enabled me to describe the phenomena of sexual expression from the perspectives of the nursing team. I am now going to turn my attention to the persons living with dementia and to understand their lived experiences of sexual expression within a nursing home context.

Lived Experiences: Person's Living with Dementia

Frank

Frank always called me 'doll' or 'hen', which are words commonly used in the west of Scotland towards a woman as a term of endearment. He had a very thick west of Scotland accent. Frank it seemed to me, was a very cheery, happy go lucky gentleman. He was always waking around the care home. He would often be reciting poetry and telling jokes to everyone he seen along the way. The poems he would narrate were usually old Scottish poems and riddles. Some of the poems Frank recited I had heard before, usually from older gentleman in pubs and social clubs. He mentioned that he used to go to the pub every Friday night and Sunday afternoon. I imagined Frank in his regular pub going around the other punters repeating one of his collection of jokes or funny stories.

Frank was very active throughout the day. He was always looking for something do to and to keep himself busy. He engaged in almost every activity that the nursing home offered the persons living there. He told me he especially loved the exercise classes, which took place a couple mornings a week. When Frank got the monthly activities sheet, he would circle when the exercise classes were on. Frank told me he was a personal trainer during his time in the army. He was a big believer in exercising for at least one hour a day. He believed that keeping your body active was not only good for one's physical health, but mental health too. Frank would invite me to either go for a walk with him or join him doing some keep-fit routines. He would direct me and show me what stretches to do to help with my core strength. Frank advised me to complete the set of exercises everyday as that would keep me in good shape.

Temporality

Frank spoke about the length of time that he had known his wife and how long they had been married. The length of time that Frank had known and spent with his wife was very important for him. The many years they have been married makes it harder for Frank to be without her in the nursing home:

*I have known my wife **for years**, I have known her since I was five and then started dating her when I was on my second leave in the army, then she agreed to marry me. I have known her for **all these years, that is a long time, a very long time**. You can't be without that person you have had **for so long**. That makes her the shining light of my life.*

Corporeality

The body was mentioned when Frank was thinking about what he missed most about being with his wife. He spoke him being physically close to his partner and how much having body-to-body contact provided him with pleasure and comfort. Frank enjoyed sleeping next to his wife and how pleasurable it is to have her body close to him at night:

*I miss my wife, **her presence you know. Cuddling and kissing** and what not. You know just wee **cuddles in bed** and things. You know she canny [cannot] sleep without me at her back, **cuddling into her back makes her feel safe and happy and makes me happy**. Its lovely and **comforting feeling her skin against mine**.*

Frank thought about being beside his wife and feeling her body against on a regular basis. He spoke about how close contact with his wife can provide him with a different level of care between the couple and how much he feels he can share more when they are experience that level of intimacy together:

*I miss more, **like sex and that**, you know the things you do in bed together. **Being naked together and kissing each other...** Even the chat you have in bed is different than the ones you have over dinner you know. **You share more when you're close together and you care more**, well I do...*

Spatiality

When Frank shared how much he misses sharing intimate moments with his wife, he spoke about the environmental space in the nursing home. He felt that there was not enough space for Frank and his partner to share a bed together and for his wife to possibly stay over and spend the night with Frank:

It's being in bed with my wife, our moments together you know... but there's no space for my wife to stay over. The bedroom is almost too wee [small] for me alone... never mind for my wife to be here with me sometimes. It's just for staying on your own.

Relationality

Frank mentioned his relationship with the nursing and care staff of the home. He spoke highly of the staff but felt that talking about his sexual and intimacy needs was not part of their job. Frank felt that some staff did not like it when he shared a sexual joke:

No I don't... no, what can they [nursing and care staff] do? They are all lovely but that is not their job to help with that is it? Some don't even like it when I tell them a joke...

Frank also mentioned that he felt he could not speak to the nursing and care staff as they do not react well whenever he tells them a humorous joke that can be viewed as 'dirty'. Frank used sexual humour to overcome his lack of intimacy he is experiencing:

Some of them [the nursing team] struggle with my sense of humour. I don't mean any harm, dirty jokes can be funny... I'm not doing it [have sex] anymore so may as well joke about it... I miss it, and I can't do it, so I talk about it in a funny way. If you don't laugh you will cry.

The Essence of Sexual Expression for Frank

The physical environment of the nursing home 'informed' Frank that he could not experience intimacy with his wife. Frank experienced sexual and intimate needs and

missed having the opportunity to be physically intimate with his wife. Frank used humour to talk about sex and to deal with the fact that he was missing sexual intimacy. Sexual and intimacy needs were not seen as a topic to discuss with the nursing and care staff.

Steve

Steve enjoyed his own company in the nursing home. The first time I had a long conversation with Steve was one afternoon, just after lunchtime. He pushed the seat out that was next to him inviting me to sit beside him. He smiled back at me once I took a seat and then asked me questions about the lunch he just had. Steve was not complimentary about the soup he received but enjoyed his steak pie. He would tap on his stomach and blame his love for food for the weight he was carrying around his stomach. Steve also blamed that fact that he enjoyed his food so much and he could not do the exercise he used to partake in. He had experienced a stroke approximately eight years ago and he used a wheelchair to assist to assist his mobility. He had the arm strength to move around the home but told me he had no power in his legs.

Steve was a big football fan. He was always wearing tracksuit bottoms and a football shirt of his favourite team. He must have had a large collection of football shirts dating back to at least the 1970s. We had a light-hearted conversation about why our individual teams are better than the other. He started telling me all the different stories he had going to the football on a Saturday afternoon. On his bedroom walls were framed football memorabilia, from signed football shirts, historic match day programmes to old ticket stubs. Steve's walls were completely covered. He was also a member of the 'Tartan Army', which is the name given to the fans of the Scottish national football team. He informed me the only time he was abroad was when he travelled to watch Scotland play in the world cup in Spain in 1982. His match ticket to watch Scotland versus Brazil, was framed and took pride of place above his bed. I enjoyed listening to his tales. He often spoke about his boisterous days when he was a younger man travelling over the country following his beloved football team.

Spatiality

Steve spoke about how he enjoyed living in the nursing home. He felt that he was living in a friendly and safe place. He repeated a few times he enjoyed the friendly people and atmosphere within his new home. Steve felt reassured that he had staff around him that could help him whenever he needed or if he had a fall or took unwell:

I do like living here. Everyone is very friendly, and I get everything done for me. It's good reassurance to know if I took unwell or something I always have someone here to look after me or get help. This is home now. It's a safe and friendly environment.

Relationality

Steve spoke about the relationships he has with the nursing and care staff who work in the nursing home. He had a good relationship with many of the staff and he described them as being friendly with Steve. He also felt that the staff were good at their job:

I do get on well with the staff in here. Most of them are lovely and I can have a laugh with them. They are good at their job and it makes a difference when they are friendly with you and you can have a laugh with them...

Steve told me he saw himself as a bit of a joker and enjoyed being a bit comical with the staff. He explained that even though a lot of the staff found Steve funny, some staff respond in ways that make Steve feel that he is a bit weird:

Some of them [nursing and care staff] don't mind even my dirty jokes, but some do look at me as if I am a bit weird.

Steve shared his feeling regarding to his own sexual expression and what aspects of sex and intimacy he missed. He felt that there was no point in discussing this aspect of his life with the staff as there was nothing that could be done. He also did not

feel he could discuss this with the nursing team as he gets the impression that some of them do not like it when he even joked about sex:

*No, no, **what can they do to help anyway?** Especially the ones that don't like me joking about it, **how can I talk to them about it?** You know, because even though it's funny and a joke, it's serious too. I think making a joke of it makes the situation light.*

Steve talked about his relationship with his wife. He missed his wife very much and often reminisced on the memories that he shared. He spoke of the relationship as someone he had a 'spark' with, and part of that relationship was the sexual part of the relationship that he and his wife had together:

*I do **miss my relationship with my wife**, she is dead now, but I think about all the good memories we had. **I miss having that spark with someone special**, in both a **friendly way** and **in an extra special way**, like ehm a **sexual way...***

Corporeality

Steve missed feeling close contact with another person. Since his wife passed away, Steven missed cuddling and kissing. He considered that having sex was out of reach for him. He did not have a partner and had physiological difficulties, but wished he could feel an intimate cuddle again:

*I miss **cuddling and kissing**. I miss being in bed with my wife, **feeling her sleeping beside me**. She has passed away now. **Having sex is a dream now**. **I'd love to feel that kind of cuddle again though...***

For Steve, being intimate evoked strong positive emotions for him. Experiencing close bodily contact and affectionate touching provided him with feelings of happiness and being loved:

*Having that bond, and **those cuddles made me feel happy**. I felt loved and happy. Also **felt wanted** and ehm... **just loved**, if that makes sense?*

Steve continued to experience sexual feelings. He is attracted to beautiful women. Steve's sexual feelings often caused a physiological reaction to his body, especially his genitals and he sees that as part of his masculinity:

*I do think about her [Steve's wife] a lot and **if I see a good looking woman it can often stir a reaction, especially down below if you know what I mean... I still find many women beautiful especially the very pretty one's, I still get those feelings that's part of who I am as a man. I think everyone you know, desires someone...***

Temporality

Steve was thinking about the last time he had sex. He said that it has be a long time since he shared a bed with a partner, and he missed it. He said that he realised that a lot of time had passed since he had a meaningful intimate and/or sexual experience:

*I mean I am an old man, I've been around **a long time, but it has been years since I have had sex. Years since I have shared a bed with a partner, I do miss it... Gosh it has been a long time, the years just fly in.***

The Essence of Sexual Expression for Steve

For Steve, the only way he could express his sexuality was through jokes and humour. Sexual expression was not something that Steve felt that he could speak to the nursing and care staff about. Steve thought about sex and intimacy and experiences sexual feelings. He believes sexual activity is a dream, but longs to experience intimate cuddles with a partner as that provides him with feelings of love and happiness. Remembering the intimate and sexual moments Steve shared with his wife, was his way of staying connected to his sexual feelings.

Ella

Ella was always immaculate and took real pride in her appearance. Her white hair was always neat and curled. She was always wearing black skirt or trousers with a colourful top, usually with a flowery pattern. She would have black court shoes with

a small block heel, which would add about half an inch onto her height and a matching handbag that she would hang from her shoulder. I admired her jewellery. Ella usually wore a matching pearl necklace and bracelet set. She had sets of all different colours. She had a white, pale pink, blue, lilac, green and a silver-grey set. She wore her pearls with pride and told me that she would not leave her room without her best jewels on.

Ella was brought up in a working-class area in the west of Scotland. She worked for many years in a café next to one of the famous shipyards on the River Clyde. She told me she would spend long hours making and serving soup, breakfast rolls, 'mince n tatties' and stoves for the men working on in the shipyards. She told me that she got through some tough times in her life. There was no choice but to work hard and you had to be on your toes dealing with all the faces and characters that she came across during her hard-working days. Ella was a confident woman. She was a grafter in her working days and was street-smart. She would not take any nonsense any not afraid to speak her mind. If she did not like something, she would let you know. If Ella was happy, she would give lots of compliments.

Temporality

Ella thanked me for having a conversation with her about sexual expression. It had been a while since Ella had engaged in a conversation about sex and this aspect of life that was important to her:

*Thank you for talking to me love, **it's been a long time since I have spoken about this...** It means a lot.*

Ella spoke about how much she enjoys spending some time alone. She said that she can be spending some time by herself in her room, but that time was spent hearing others outside her room and staff often walking into her room. Ella felt that her alone time was not truly private and alone. She imagined that if her husband was still living that she would want to experience alone time with him with minimal interruptions:

*If my husband was still alive, **I would want alone time in here**, but I am not sure it can happen... It's the talking outside that is annoying. I certainly wouldn't be doing anything like having sex or lying naked with a man. That is private and people would know or **you wouldn't be able to enjoy your alone time** hearing everyone outside.*

Relationality

Ella spoke about the joys and happiness she felt having a husband who she felt close and connected too. She said that having a happy marriage and lots of intimacy, made her relationship better and added a specialness to the relationship:

*I felt my happiness with my husband... He was a special one, and **he made me feel special. Having that relationship and a relationship with eh, intimacy is special... Very special.***

Ella told me that she had a good relationship with the nurses and carers working in the home, but felt unable to have a discussion about sexual expression. She felt that the staff see the older persons living in care homes in a similar way to grandparents, which would make the staff feel embarrassed if they started talking about their sexuality:

*...think **they see us like their granny** and their granny doesn't have those feelings do they? **They look after us well** and **I get on well with them** but no, never talk about sex. They are lovely, but I think **they would be so embarrassed...***

Corporeality

Sexual feelings were important to Ella. Feeling 'sexy' was an experience that Ella continued to have as she grows older and has not stopped since living in the nursing home. She keeps these emotions to herself:

*I still think about it, **I still have those feelings...** You know when you think about it you get **'those feelings'**. You know **those feelings when you feel***

sexy and want to do it [have sex]... I get those feelings, but just keep it to myself...

For Ella, having sexual feelings and experiencing sexual activity made her feel more attractive and feminine. She initially said that feeling sexy, made her feel like 'a girl', but she quickly changed her language and replaced 'girl', with 'a lady, a woman'. Ella's femininity was often expressed through her sexuality:

I still like to feel like a woman and think about it... You need to feel sexy and attractive, that made me feel like a girl, not girl uhm... a lady, a woman... I always felt lovely and ehm feminine when I was in bed.

Ella missed close contact with another person and physical touch. She spoke a lot about how kissing, handholding and skin-to-skin contact was something that she has missed since her husband has passed away:

I do miss kissing and holding hands and those touches against your skin... that's nice I do like that.

Spatiality

The body was import to Ella in terms of space. The shower was a space where nakedness was acceptable for Ella. She believed that any other environment in the home, nakedness was not acceptable. She felt that it was not fair for staff to see her naked unless helping her with her personal care:

It is different in the shower, they are washing you so have to see you naked, anywhere else I wouldn't be naked that's not fair on anyone...

Ella feels that moving into a care home means her sexual life is finished. She feels she is in a care home because she needs help with personal care and to do certain activities. Ella spoke about the physical environment and furniture and claims that a nursing home is not set up for intimate relationships:

*It's a part of life, but I do feel **it is a part of life that has finished since living here...** I think because we are all old **in here, we are here** to get help getting washed and dressed, play bingo, **sit in front of the telly** watching rubbish, **we are not here to talk about sex, or have it...** I mean **look at my bed**, it's not big enough for me, never mind to have sex in it. I'd fall off and break my hip...*

The Essence of Sexual Expression for Ella

Ella believed that expressing her sexuality meant a person must be having sexual activities. However, Ella had sexual thoughts and feelings, and enjoyed speaking about sex but had not done so for a long time. Sex and intimacy were a topic that is embarrassing for Ella to speak to the nursing and care staff about. If Ella's husband were still alive, Ella would have enjoyed spending intimate times with her husband, but unsure if that is able to happen in the home. Being close with her husband and having sexual feelings made Ella connect more with her femininity.

Archie

Archie usually spent most of his day in his room. It would vary if he wanted to use the dining room to enjoy his meals or whether he was just happy to spend his day in his room. Archie enjoyed one walk a day in which he would circuit the building. He would keep an eye on the sky and the clouds to try and judge what time of day it would be best to get outside for his walk. If the weather was miserable, Archie would take a wander around the home, but do about two laps as he considered it to be a lot shorter than if he did a circuit of the grounds outside.

Archie walked with a brown wooden stick and always put a bowler hat on when he went for his walk, no matter whether he was doing his walk inside or outdoors. When I accompanied Archie on his walk he turned into a great storyteller. He left school to join the navy and spent over fifteen years in the Royal Navy. He was very proud of his Royal Navy experiences. He received medals for his natural service, which he wore proudly on his suit jacket every Sunday. He also had many souvenirs of navy ships on positioned proudly on his shelves in his room. On the window

ledge, he had approximately 10-15 books about famous Navy ships and navigation. Archie was still fascinated about the Royal Navy, navigation and enjoyed watching World War Two documentaries. When Archie retired from the Royal Navy, he set up a picture framing business with his son-in-law. He liked the calm steady nature of having a picture framing shop. Archie said it was a great contrast to his busy and noisy life at sea.

Spatiality

Archie spoke about the physical environment of the nursing home in relation to sexual expression. He mentioned the size of his room. The furniture within the room was not ideal for Archie to share intimate moments with his wife and express their connection together. When Archie considered spending some quality time with his wife, the space became a significant barrier:

*I mean if you look at the **size of the place**, there is no double room bed. Or sorry, **double bedded room** I meant. I mean, she visits me, but **there's not enough room in there for both of us**. I mean they are perfectly comfortable for me, but not the two of us.*

Archie spoke about the positives and the negatives of living in the nursing home. The nursing home environment provided him with safety and shelter. He said that the reasons he had to move into the nursing home was because his wife had a hip injury and he could not look after her well enough as he received a diagnosis of dementia. The worst and most upsetting aspect of living in a nursing home was that he is no longer living with his wife:

I am in here** because my wife had an accident and broke her hip, I couldn't look after well as I was starting to suffer with the dementia at the time... I mean **I have a roof over my head, but I miss her** [Archie's wife] when she isn't here. **That is the worse bit about living here.

Relationality

Archie said that him and his wife had a happy marriage and would experience physical and sexual intimacy. The intimacy in their relationship occurred right up to

Archie's wife having her accident and then Archie moving into a nursing home. Archie said he knew that moving into a nursing home would mean that his intimate relationship with his wife would come to an end:

I wish me and my wife could still be together. I'm 94 now and that is all because of her. She is the spark that keeps me going... We have a good marriage and we were getting on fine with respect to intimacy prior to her having the accident and me coming in here. We knew that part of life would finish when we come in here. It just is what it is, no point crying over spilt milk...

Relationality was also spoken of in connection with Archie's relationship with the nurses. He complimented some of the nurses in relation to him receiving care, but did also say that some of the nurses were distant with Archie. He believed that many of the nurses would not be interested in having a conversation with Archie and would think that, as an older gentleman, he would not be interested in sexuality or having any sexual feelings:

No one has ever spoken to me about this. Some of them [nurses and carers] are very good, but some are very distant and won't be able to help you... I would talk to them about it, I just don't think they are mature enough. It wouldn't occur to them that an old fud like me would be interested in being in bed with someone...

Temporality

For Archie, the length of time he was married to each other, which was approximately seventy years, was important to him. He believed the longer he was married to his wife, the more he felt he needed to be with her, and their connection was important to Archie:

I have been married for a long long time. When you have been married for that length of time, you need each other.

Corporeality

The body was important to Archie with respect to how he shared intimacy between his wife and himself. He spoke about how being physically close to his wife was important to expressing his sexuality and the intimacy between them:

*We would still enjoy time in bed together, **lots of cuddles and kisses**. I used to **touch all over her skin**, she seemed to enjoy that. It would send her to sleep. We would still do more than that, but **it was all about being close to one another**.*

Archie mentioned the physiological and sensational changes that he experiences as he gets older. He spoke about the positives and the negatives of his bodily sensations as he ages. When Archie experiences an ache or a pain, he feels it more as he grows older. He says that with 'good feelings', such as sexual feelings becoming stronger. Even though the intimacy and sexual feelings he was experiencing was not as frequent, they become more special as he gets older:

*I know I am an old man now, but **my body still feels the same as it used too. It's a bit slower, well a lot slower and a few aches and pains**, but I still feel like myself. I think your **skin actually gets more sensitive when you are older**. You experience things more. Like **when you are sore it seems to be even sorer** when you are older. But, that works the other way too... **When you have good feelings, sexual feelings it's stronger**. Might not get them as often, but when you do, **they become more ehm, special**.*

The Essence of Sexual Expression for Archie

Archie took it as a given that the sexual and intimate aspect of his relationship with his wife would end as he moved into the nursing home. He thought that the nurses and carers would not consider that sexual expression was important for Archie. He saw the physical environment of the nursing home a significant barrier for him continuing his sexual connection with his wife, especially that there were no double beds. Physical contact was very important for Archie and he missed the feel of touching his wife's skin. For Archie, the body becomes more sensitive as he grows

older, which means for him, he experiences sexual feelings less frequently, but such feelings are stronger.

A Synthesis of the Essence of Sexual Expression in Persons Living with Dementia

Through writing the phenomenological descriptions of the persons with dementia's lived experiences of sexual expression, the essence of sexual expression for the participants were revealed. Just like the nursing team's experiences, by synthesising the persons living with dementia's descriptions there was a risk that my interpretations of their experiences could move too far away from their experiences and the raw data. Therefore, I followed the same process as I described when synthesising the nursing team's descriptions and essences, where I extracted the key words and phrases, or 'gems' within my interpretative phenomenological descriptions, and then with the raw data and cross-checked them with one another. By focusing on the descriptions through the lenses of the lifeworld's existentials, the following eight essences have emerged which represent my interpretation of the essence of sexual expression for persons living with dementia:

- A need for intimacy and human connection.
- An element of a person's gender identity
- A deep sense of feeling loved, special and experiencing happiness.
- A desire to be physically close to another and for sexual touch.
- Experiencing and expressing pleasurable sensations through a more sensitive aging body.
- Reminiscing about and/or grieving for meaningful sexual relationships, both past and present.
- Insufficient time, space, and privacy in a nursing home environment.
- Using humour as a way of making a serious subject light-hearted.

I am suggesting that these eight elements form the essence of sexual expression for persons living with dementia. However, to reiterate, it is important to recognise that not all the participants experienced all eight elements at any one time.

The Phenomenon and Lived Experience of Sexual Expression in Persons Living with Dementia

Through a process of continuously engaging with the essences of sexual expression for the persons living with dementia, with returning to the phenomenological descriptions and original transcripts, I created definitions describing the phenomenon and lived experience of sexual expression in persons living with dementia. Just like the nursing team definitions, I shared potential descriptions with others such as my supervisors, fellow PhD candidates and the care home manager. I received feedback on their thoughts and how relatable the definitions were to them, which helped me create two definitions. The first is to describe the phenomenon of sexual expression in persons living with dementia. The second definition illustrates the persons living with dementia's lived experience of sexual expression whilst living in a nursing home.

I propose the phenomenon of sexual expression in persons living with dementia to be:

An embodied manifestation in which a person living with dementia expresses sexual sensations and/or desires ranging from sexual intimacy needs, meaningful human relationships and their gender identity.

The lived experience of sexual expression in persons living with dementia, living in a nursing home is:

A pleasurable part of life with feelings of being loved, reminiscing about and/or grieving for previous and present sexual relationships, but difficult to express within the context of a nursing home.

Summary

I have now reached a point where through my phenomenological writing and existential reflection, I have moved closer to understanding the phenomenon of sexual expression in persons living with dementia as experienced by both nurses and persons living with dementia in a nursing home context. I have

created four enriched definitions that capture the phenomenon and the lived experience of sexual expression for both participant groups. *Table 5* recaps the four definitions that I have created through this research.

Table 5: My Definitions of Sexual Expression in Persons Living with Dementia

<p>Persons Living with Dementia</p>	<p>The phenomenon of sexual expression in persons living with dementia:</p> <p><i>An embodied manifestation in which a person living with dementia expresses sexual sensations and/or desires ranging from sexual intimacy needs, meaningful human relationships and their gender identity.</i></p>	<p>The lived experience of sexual expression in persons living with dementia, living in a nursing home:</p> <p><i>A pleasurable part of life with feelings of being loved, reminiscing about and/or grieving for previous and present sexual relationships, but difficult to express within the context of a nursing home.</i></p>
<p>The Nursing Team</p>	<p>The phenomenon of sexual expression in persons living with dementia as experienced by nurses:</p> <p><i>A dynamic spectrum of various acceptable and unacceptable expressions, the meaning of which is predetermined by the nurses, and is grounded in perceiving the ageing body as desexualised.</i></p>	<p>The lived experience of caring for persons living with dementia in a nursing home who express their sexuality:</p> <p><i>A challenging and uncertain element of dementia care, which is often forgotten about, evokes feelings of discomfort and anxiety, and is easier to ignore or respond using distraction or humour.</i></p>

Looking at the definitions above, there is a deep sense that there are strong differences in how sexual expression is perceived and lived by persons living with dementia, and the nurses caring for them. Initially, when looking at the definitions for persons living with dementia, I feel inspiration, hope, and sadness all at the same time. I feel inspired and hopeful because here within the definitions that the participants spoke of their sexual expression in glowing terms. Nevertheless, I felt a notion of sadness, hearing how the participants felt

that they almost always regarded as something from their past and could not express an enjoyable part of who they are, when moving into a nursing home. When focusing in on the nursing team's definitions, I gain a sense of struggle, uncertainty, and complexity. Unironically, the feelings that evoke within me when reading the definitions, are very similar to the emotions I experienced when speaking with the participants, reflecting on their conversations, and writing their descriptions. When I reflect deeper upon the definitions, I see potential. Potential for sexual expression to be considered a meaningful part of a person's way of being and an aspect of life that is important for many, like the participants in this research. I also see potential for sexual expression to be viewed in a holistic way rather than through a behaviouralist lens, as this may reduce those feelings of struggle, uncertainty, and complexity for the nurses. Thus, gaining an understanding of the significance of sexual expression from persons living with dementia themselves, has the potential to contribute to dementia care and remove those feeling of uncertainty and embarrassment for the nursing team. This will be discussed in more detail in Chapter Nine.

Conclusion

Through the process of synthesising the data through phenomenological writing with the four existentials, to creating the summary of essences of each person, before synthesising the essences for both the nursing team and the persons living with dementia, I have hopefully evoked strong insights and understandings of the meaning of sexual expression in persons living with dementia. I have got close to touching the phenomena of sexual expression for the persons living with dementia and what it feels like to express sexuality whilst living in a nursing home. In addition, I have described the phenomena of sexual expression in persons living with dementia as experienced by nurses, and what it feels like to experience sexual expression when caring for persons living with dementia. In the next chapter, I will be using the new knowledge from this research, alongside outcomes from similar research, to offer an expanded appreciation of the phenomenon of sexual expression in persons living with dementia. I will also return to my philosophical

ideas and new theoretical framework to situate the findings from this research in the context of a new practical framework, The Sensuous-Sexual Expression Framework.

Chapter Nine: Discussion and Theorising

Introduction

In this chapter, I expand on the research findings and place the phenomena of sexual expression in a broader context; to sensuous-sexual expression. I reflect further on the phenomenological descriptions I created in the previous chapter and revisit the essences to keep me close to the lived experience for the participants. As Finlay (2011) suggests that the purpose of phenomenological research is not to present 'answers' from the data which has been collected, but rather that its purpose is to capture something of the complexity of human nature. Thus, with radical reflection, focused discussion and skilful presentation, I aim to 'bring the phenomenon to life' (Finlay 2011 p. 244) in an original way. I aim to do this by revisiting the Sensuous Framework and present a practice framework as uncovered through the data collection and analysis. I am calling this 'The Sensuous-Sexual Expression Framework'.

Table 6 presents the essence of sexual expression for both the nurses and persons living with dementia, along with the possible interpretations and meanings that were concealed to me until I dwelt on them in depth. Focusing on the nursing team, I found four concealed meanings, albeit all tangled up with one another, buried within the phenomenon of sexual expression in persons living with dementia as experienced by nurses: (1) personal values and beliefs on older person's sexuality, (2) cultural norms around sensuous-sexual expression; (3) the ageing body and (4) lack of awareness and education. For persons living with dementia, I found three concealed meanings that I saw in the findings from the persons with dementia, again all tangled up with one another. I have attempted to untangle the experience of the participants and constructed the meaning of sexual expression as lived out in the context of the nursing home. The three unconcealed meanings from the persons living with dementia were: (1) embodied sensuous-sexuality; (2) meaningful sexual relationships and (3) sexuality and nursing home culture.

The essence of sexual expression in persons living with dementia, and the possible interpretations have influenced the creation of a practice framework. Therefore, this chapter will focus on describing the Sensuous-Sexual Expression Framework, which has been revealed through the participants' experiences of sensuous-sexual expression. I then conclude this chapter by offering implications for practice, research and education.

Table 6: The Essence of Sexual Expression and Possible Interpretations

	Essence of Sexual Expression in Persons living with Dementia	Possible Interpretations
The Nursing Team	<p>An attribute of being a person forgotten about or not considered important for flourishing.</p> <p>A human desire which is not associated with older persons living with dementia.</p> <p>Considered as a private aspect of a [younger] person's life.</p> <p>A dynamic spectrum of various expressions, with some being acceptable and others unacceptable.</p> <p>A challenging aspect of dementia care giving which evokes feelings of embarrassment, uncomfortableness and/or shock.</p> <p>Easier to ignore, desexualise, use distraction techniques or approach with humour.</p> <p>Uncertainty on how to be person-centred and what is the right thing to do.</p> <p>Unsure of any meaning behind the expression and how the person is feeling.</p>	<p>Personal values and beliefs on older person's sexuality. Cultural norms around sensuous-sexual expression. The aging body.</p> <p>Personal values and beliefs on older person's sexuality. The aging body.</p> <p>Personal values and beliefs on older person's sexuality. Cultural norms around sensuous-sexual expression. Lack of education.</p> <p>Personal values and beliefs on older person's sexuality. Cultural norms around sensuous-sexual expression The aging body.</p> <p>Personal values and beliefs on older person's sexuality. Cultural norms around sensuous-sexual expression.</p> <p>Personal values and beliefs on older person's sexuality. Cultural norms around sensuous-sexual expression. Lack of education. The aging body.</p> <p>Cultural norms around sensuous-sexual expression. Lack of education.</p> <p>Personal values and beliefs on older person's sexuality. Moral and cultural norms around sensuous-sexual expression. Lack of education.</p>

	Anxiety around the perspectives and opinions of families/legal representatives and the primary desire to please them.	Cultural norms around sensuous-sexual expression. Lack of education.
Persons Living with Dementia	<p>A need for intimacy and human connection.</p> <p>A desire to be physically close to another and for sexual touch.</p> <p>An element of a person's gender identity.</p> <p>A deep sense of feeling loved, special and experiencing happiness.</p> <p>Experiencing and expressing pleasurable sensations through a more sensitive aging body.</p> <p>Reminiscing about and/or grieving for meaningful sexual relationships, both past and present.</p> <p>Insufficient time, space, and privacy in a nursing home environment.</p> <p>Using humour as a way of making a serious subject light-hearted.</p>	<p>Embodied sensuous-sexuality. Meaningful sexual relationships.</p> <p>Embodied sensuous-sexuality. Meaningful sexual relationships.</p> <p>Embodied sensuous-sexuality.</p> <p>Embodied sensuous-sexuality. Meaningful sexual relationships.</p> <p>Embodied sensuous-sexuality.</p> <p>Meaningful sexual relationships. Sexuality and nursing home culture.</p> <p>Sexuality and nursing home culture.</p> <p>Sexuality and nursing home culture.</p>

The Sensuous-Sexual Expression Framework

In the previous chapter, I developed a rich description of the phenomenon of sexual expression in persons living with dementia from the research data. However, now this definition describes 'sensuous-sexual expression'. Sensuous-sexual expression incorporates a much broader understanding of persons living with dementia as both sensuous and sexual beings. The definition of 'sensuous-sexual expression' appreciates that sensuousness and sexual expression are woven together and

intrinsically connected, and sexuality is expressed through our sensuousness. I am defining 'sensuous-sexual expression' as:

An embodied manifestation in which a person living with dementia expresses sexual sensations and/or desires ranging from sexual intimacy needs, meaningful human relationships and their gender identity.

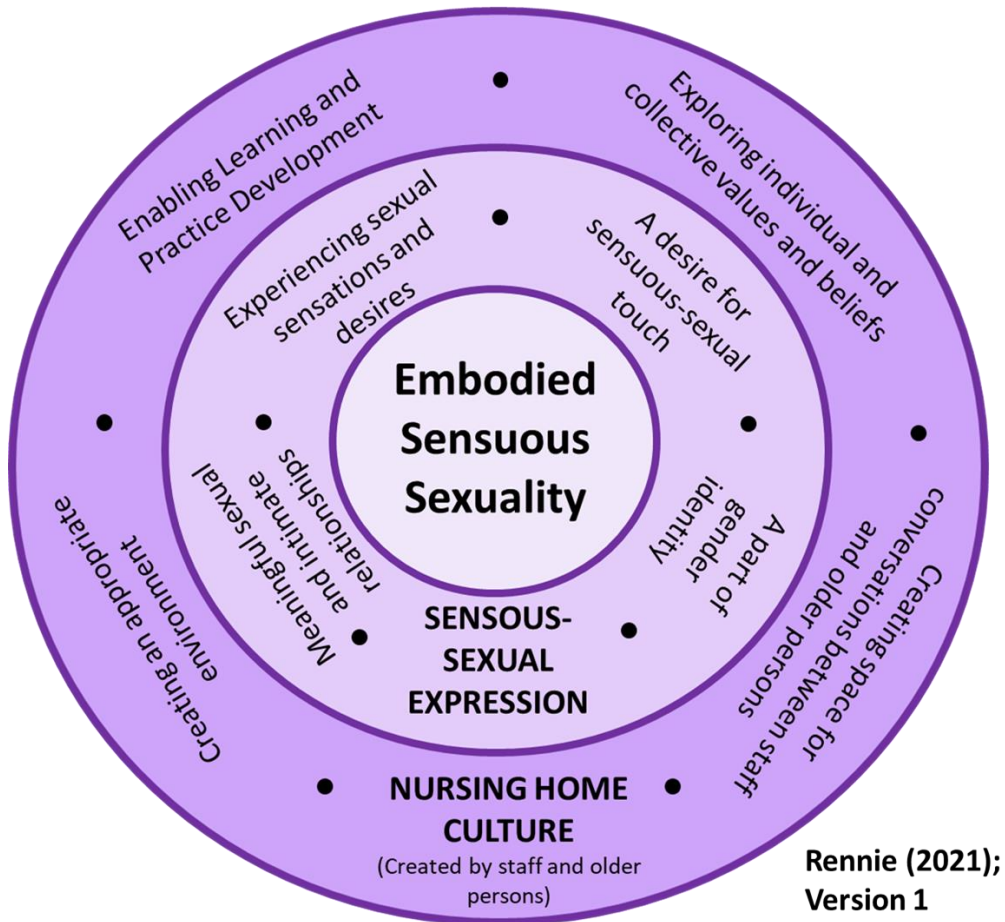
I have adapted the Sensuous Framework, which is philosophical and conceptual in nature, to the Sensuous-Sexual Expression Framework, which has evolved from the research findings. From this research it suggests that persons living with dementia see themselves as sexual beings and what they experience through their body is part of this. This study emphasises that the same is true for older persons with dementia who are living in a nursing home, however the nursing home environment and culture can prevent older persons living with dementia to express who they are as sensuous-sexual beings. For the participants living with dementia, embodied sensuous-sexuality is connected through their feelings, pleasures, sensations and desires. This is the first time, which persons living with dementia have been shown in such light and have been included in research that explores sexual expression. Taking the findings from this research, I created a Sensuous-Sexual Expression Framework, to support nurses in practice to have conversations about sexual expression and to give some insight about what sexual expression may mean for persons living with dementia.

If we focus on the phenomenon of sensuous-sexual expression in persons living with dementia as experiences by the nurses and their lived experience of it, sexual expression is viewed as a challenging aspect due to the fact that there is a lack of awareness, understanding and appreciation on the sensuous capabilities that persons living with dementia have and that sensuous-sexual expression is embodied. The discomfort around sexual expression came from personal values of older person's sexuality and cultural norms around sensuous-sexual expression in later life. Sensuous-sexual expression is seen as uncertain by the nurses because they are seeing a person expressing sensuousness, which in this case is sexual

expression, without understanding the underlying layers behind the expression, i.e., the emotions, senses and desires in which the person is experiencing. There was a clear lack of understanding or knowledge about how sensuous-sexual expression stems from embodiment and bodily emotions, desires and senses. I cannot help but wonder what the experience of sexual expression in persons living with dementia would be for the nurses, if they heard the experiences of the residents that participated in this study and had a framework available to them, in which can be the foundation of knowledge and clinical practice in regards to sensuous-sexual expression. Therefore, the Sensuous-Sexual Expression Framework has the potential for nurses to consider the meaning of sensuous-sexual expression in persons living with dementia, and can be used as a guide in practice to provide person-centred care.

The Sensuous-Sexual Expression Framework (*figure 13*) essentially encompasses three sections, or 'layers'. This first is embodied sensuous-sexuality, which is shown in the inner layer, or the core, of the framework. This part of the framework focuses on the notion that sensuous-sexuality is a unique part of personhood and sexual desires and sensations is indeed embodied. The second concept that can be seen in the middle layer is 'sensuous-sexual expression'. This section provides descriptions and possibilities to why older persons living with dementia may express their sensuous-sexuality. The third aspect of this framework is focusing in on nursing home culture and how certain aspects can influence how persons living with dementia can express who they are as sexual beings.

Figure 13: The Sensuous-Sexual Expression Framework



Embodied Sensuous-Sexuality

This research has shown that sexuality is not a cognitive and rational concept that diminishes with a diagnosis of dementia. Persons living with dementia experience sexual desires, have intimacy needs and long for pleasure and intimate connections. They are sexual beings and the need to express one’s sexuality is a meaningful aspect of who they are as persons. Sexual expression is part of who we are as sensuous beings, in that it is our bodily emotions, desires and senses connects person to being-in-the-world, and this needs to be acknowledged in person-centred dementia care.

This section of the framework places greater emphasis on the body and our ability to experience emotions, desires, and senses and the importance of gratifying those emotions, desires and senses. Rather than seeing our bodily desires as meaningless, we need to celebrate our body as it is through our ability to experience emotions, desires and senses and appreciate it is through our body that we are in touch with who we are as individuals and our world. Sensuous-sexual expression needs to be viewed from the perspective that our body and its capacity to experience emotions, senses and desires is at the core of our very being. This research showed that persons living with dementia are sexual beings in a sensuous human body. Our sexual desires and feelings contribute to who we are as humans and it is through our bodies in which we express ourselves and respond our sexual and intimate needs. In other words, our sensuous-sexuality comes from our deepest roots of emotion and our interactions with our worlds. If we recognise this, then sensuous-sexual expression has the potential to be appreciated in persons living with dementia. To highlight this position, I have called this section 'Embodied Sensuous-Sexuality'.

The word 'sensuous' is very rarely used within nursing and in the dementia care field. However, it has had some recognition and it is important to identify how it has been used up to this point. In recent times, Twigg (2010) explores the subject of clothing within the dementia care field and argues that clothes continue to be significant in the lives and wellbeing of people living with dementia, and has a unique role in the maintenance of personal identity. Twigg (2010) claims that in the presence of cognitive impairments, clothes still influence individuals in terms of how garments feel and look, at a direct and sensuous level:

'If you're losing a lot of cognitive function, your world becomes more sensory and more immediate. And so it's a way of still knowing...'

Twigg (2010 p, 286).

As Twigg (2010) points out, our clothes represent self-identity, comfort and autonomy. We (usually) select what we like to wear and what we feel good

wearing. Twigg's (2010) exploration on the importance of clothes and personhood for people living with dementia, offers some useful insight into how our sensuousness can be our way of connecting to our personhood. Further within dementia care, the Positive States of Mind (PSOM) scale (Horowitz et al. 1988) is a tool which measures wellbeing in persons living with dementia and measures focused attention, productivity, responsible caregiving, restful repose, sensuous pleasure, and sharing. Sensuous pleasure is defined by Horowitz et al. (1988) as able to:

'enjoy bodily senses, enjoyable intellectual activity, doing things you ordinarily like, such as listening to music, enjoying the outdoors, lounging in a hot bath.'

(1988 p, 481)

Horowitz et al. (1988) have brought to focus some vital examples of how we experience sensuous pleasure. For example, relaxing in a bubble bath can be a tantalising sensuous experience. The warm water against one's skin, the fragrance of the bubble bath solution, with the soothing sound of your favourite tranquil music can provide bodily pleasures. However, what it is important to point out that Horowitz et al. (1988) has described sensuous pleasures as explicitly non-sexual. It is worthy that scholars are thinking about the importance of bodily senses and pleasures and acknowledging sensuous experiences such as taking a walk-in nature, enjoying a swim in the ocean or sipping your favourite wine. This begs the critical question of *'why do we separate sexual feelings, pleasures and sensations away from our sensuousness?'* This research has challenged the notion that sexual expression should be fragmented from our sensuous capabilities. Sexual desires and pleasures are a bodily experience which stem from our emotions, senses and desires just like other bodily pleasures. Older persons living with dementia connect with their embodied sensuous-sexuality and experience pleasurable sensations through a more sensitive, aging body. The Sensuous-Sexual Expression Framework

connects with this by incorporating all emotions, senses and desires and does not exclude sexual needs and expression away from other sensuous experiences.

Sensuousness in a non-sexual way seems to be looked at positively in dementia care, for example, incorporating care around musical therapy, aromatherapy, making sensory rooms available etc., but this research has shown that sexual desires seem to be looked negative or more difficult. This reinforces that ageist assumptions underpin societal perspectives surrounding older persons and sexual expression. Sensuous-sexuality challenges those ageist stereotypes. The Sensuous-Sexual Expression Framework has the potential to give a different perspective on other personal expressions, it also claims that sexual emotions and desires are a part of our human experience. Just as Salami (2020) claimed, sensuous is not a replacement for sensual, where sexual pleasures and desires dominate its connotations. Nevertheless, we should not forget the erotic potential that sensuousness can bring. As sensuous beings, our sensuousness incorporates all emotional and sensory aspects of life and part of this is erotic experiences.

Overall, when persons experience a decline in cognitive ability, such as persons living with dementia, the world become a much more sensory and intimate place, and people are more likely to express what they are sensing and feeling and use their bodies to make sense of their emotions. This research shows that there is a need for a greater focus on sensuousness in persons with dementia and the increasing importance of sensuousness as part of communication and experiencing the world. As cognitive capacity alters and declines, sensuous perception and experience come more to the fore. Embodied sensuous-sexuality recognises that persons living with dementia are responding to what they are perceiving and experiencing through their bodies and recognises that sexual feelings and desires are meaningful to many older persons.

Sensuous-Sexual Expression

This section of the chapter focuses on the middle layer of the Sensuous-Sexual Expression Framework. I have called this part of the framework, 'Sensuous-Sexual

Expression'. As described above, the inner layer of the framework highlights that persons are embodied sensuous-sexual beings and is an important aspect of human existence. Sensuous-sexual expression builds on this position, and describes possible reasons behind the need for sensuous-sexual expression in older persons living with dementia, that have emerged from the research findings. This part of the framework aims to give nurses a greater and a more person-centred understanding of sensuous-sexual expression.

Meaningful Sexual and Intimate Relationships

This research has shown that one of the most challenging aspects of moving into a nursing home is the loss of meaningful sexual intimacy in relationships for older persons. Ehrenfeld et al. (1997) have argued that the term 'intimacy' covers a spectrum of emotions, needs and activities ranging from feelings of caring, closeness and affection that go with companionship (which may or may not involve sexual feelings or activity) to romantic feelings. Intimacy, whether sexual, emotional or indeed both, is not well explored within literature when it comes to persons living with dementia in nursing homes. Couples, where at least one person is living with dementia, wish to maintain a sexual relationship and enjoy experiencing sexual intimacy as a source of comfort, reassurance and mutual support. Perhaps the most common scenario there will be is when a person with dementia moves into the care home and the partner without dementia is still living in their own home. When partnerships have formed before entry to a care home, family and friends are often (though not always) supportive and expect the relationship to continue in some way but may forget the importance of the physical intimate aspect of the relationship. In addition, nurses and other care workers may be uncomfortable and reluctant to acknowledge or support the sexual aspect of their relationship.

Sexual intimacy, whether kissing and cuddling, or sexual intercourse remains important with age and providing a greater attention to sexuality and intimacy has the potential to contribute to the quality of life of persons living with dementia, and potentially their romantic partners. One of the most difficult aspects of living in a nursing home for the older persons was not living with their partners. Having a

meaningful relationship, but unable to be physically intimate is difficult for residents living in a nursing home. Many older persons living with dementia have been in a meaningful sexual relationships for a significant length of time, and even though the relationship can continue, there is an element of loss when it comes to the sexual aspect of the relationship. Sexual intimacy with a partner has the ability to bring older persons living with dementia comfort, familiarity and closeness. There is also potential that the partners of residents living in nursing or care homes also miss intimacy within their relationship.

There is a widespread view that persons living in long-term care settings still think about sexual intimacy, and moreover, it was recognised that this was perfectly 'normal'. This is also true for persons who are widows or do not have a long-term partner. Sexual intimacy is often thought about, and older persons reminisce about their previous sexual relationship(s). Some older persons living with dementia are open to entering new relationships, if the opportunity should arise. Having a dementia diagnosis and living in a nursing home does not stop older persons from wanting to be part of a meaningful relationship and to experience a sexual connection with another person. Overall, meaningful sexual relationships, and the expression of one's sensuous-sexuality through a meaningful sexual relationship, is important for persons living with dementia who are living in a nursing home and is an aspect of life they continue to enjoy reminiscing about or wish to continue.

Experiencing Sexual Sensations and Desires

Embodied sensuous-sexuality is the full expression of your sexuality through a person's emotions, desires and senses. This research shows that embodied sensuous-sexuality is part of the presence of being for older persons living with dementia. The older persons living with dementia continue to connect to their sexuality and are engaging directly with the experiences they perceive and feel. They continued to experience sexual sensations and desires, and they recognised experiencing such sensations and desires were part of who they are as individuals. Staying connected with ones embodied sensuous-sexuality evoked feelings of being loved, happiness and joy for persons living with dementia.

Sexual feelings and desires that older persons experience, contribute to the need of human touch and intimacy. Giving and receiving affection is considered special with persons living with dementia and those feelings in some ways become stronger as persons age. Sexual sensations and desires may not be present as frequently as previously in a person's life, but this research showed that due to increased body sensitivity, older persons in many ways experience stronger sexual sensations. The participants living with dementia described their ageing body as slower and tender, due to increased sensitivity. Nevertheless, this increased sensitivity has created a positive effect on his embodied sensuous-sexuality, in that when older persons experience sexual feelings, those feelings become more powerful and as one participant described it, 'more special'. Therefore, sensuous-sexual expression can be a result of experiencing sexual and/or intimate feelings through one's body and it can be a powerful, emotive and meaningful experience for older persons living with dementia.

A Desire for Sensuous-Sexual Touch

This nicely follows onto the concept of sensuous-sexual touch. Persons with dementia, who are living in nursing homes miss being touched intimately by a long-term romantic partner. The feeling of being naked, touching and being touched, was a bittersweet memory for the participants in this research. The older persons living with dementia enjoyed remembering their sensuous-sexual moments with a partner and spoke about a range of pleasurable memories which involved sensuous-sexual touch, especially lying in bed with a partner. However, there was also a sadness amongst the older person living in the nursing home, as they believed that having sensuous-sexual touch and being intimate with a partner was not possible in the nursing homes.

The experiences that the nursing team participants were sharing, where a person living with dementia would touch the caregiver's body or say a sexual comment were all featured around moments of nursing assisting with personal care. In many situations, the person with dementia is alone with someone, being undressed or is completely naked and being given personal care. For many, the only other time

situations where nakedness and touching are involved is in a sexual context (Twiggy 2006; Lawler 1991), a time where human sensuous is arguably most heightened. Therefore, the response of the person living with dementia could be an expression of their sensuousness and a way of communicating the need for contact of an intimate and/or sexual nature.

A Part of Gender Identity

There was a strong connection between sensuous-sexuality and gender identity for the participants. The older persons living with dementia felt that their sensuous-sexual expression related to their 'masculinity' or 'femininity'. Furthermore, part of their gender identity were expressed through the participant's sexual desires. Having an attraction to another person, and desiring sexual touch and intimacy with another person was a pleasurable feeling that persons living with dementia were familiar with. These sensations were an enjoyment for the participants and were believed to be connected with expressing their masculinity or femininity. This highlights further that sensuous-sexual expression is part of persons embodied sensuous-sexuality and continues to be pivotal as persons get older, including persons living with dementia.

Usually, gender and sexual expression gets viewed as a sexual function issue, with an emphasis on whether persons are able to have and enjoy sexual intercourse (Greer 1992; Calasanti and Slevin 2001; Marshall 2006; Sandberg 2015). According to Sandberg (2015), sexual function in later life has been the object of thorough discussion and considerably less attention has been given to the question of sexual desire, for both women and men. For the participants in this research study, it did not seem to the desire for sexual intercourse that was most important. Sexual intimacy, such as sharing a bed with a partner, desiring the closeness and touch of another person, and being desired in return appeared to shape the relation between gender identity and embodied sensuous-sexuality. This research clearly highlights the embodied and sensuous perspective of sexuality, rather than biological-functioning sexuality and is the first to focus on older persons living with dementia in such a way. The participants placed more emphasis on the emotions

and desires of sensuous-sexual expression, rather than the functioning-anatomy perspective. Overall, sensuous-sexuality is part of older person's identity and their uniqueness. This research showed that older person living with dementia appear to embrace how their body and sexuality has changed through ageing.

The Nursing Home Culture

The final section of this framework is the outer layer, which I have called 'The Nursing Home Culture'. It is clear from this research that the nursing home culture influenced and impacted on the how persons living with dementia could, or could not, express their sensuousness and sexual sensations and desires. Therefore, this section will take the findings from this study and discuss how the care home culture can support sensuous-sexual expressions in older persons living with dementia and recognise them as sensuous-sexual beings. It is important for me to state that nursing home culture is not only directed at staff working in the home. The culture is also created by older persons living in the home and coming from a person-centred perspective, older persons should be active participants in contributing to cultural work.

Exploring Individual and Collective Values and Beliefs.

When looking deeper at the essence of sensuous-sexual expression in persons living with dementia as experienced by the nurses, much of the nurse participant's experiences, thoughts and concerns stemmed from their own personal values and beliefs on older person's sexuality in general. All the nursing team participants spoke about their discomfort, uneasiness and their own assumptions of older person's sexuality to a certain degree. There was no doubt that this research highlighted that sensuous-sexual expression from persons living with dementia evoked strong feelings of embarrassment, uncomfortableness and/or shock. Overall, any form of sensuous-sexual expression was considered inappropriate and the nurses felt that this was something they must respond too in some way that made the experience better for them. This was usually done through distraction techniques, using humorous comments or ignoring the expression. The nurses used

this as coping strategies as they felt unequipped to deal with sensuous-sexual expression any other way.

This research found that the personal values influence what is considered as acceptable and unacceptable with regards to sexual expression in persons with dementia, and often stem from cultural norms around sexuality and ageing. It was clear that the nursing team positioned sensuous-sexual expression through a behaviouristic worldview, rather than seeing sexual expression as sensuousness. I envisioned this idea that some expressions are acceptable whilst other unacceptable just like a continuum or a spectrum. I have called this a 'dynamic spectrum' of various expressions. The reason I have described this as a 'dynamic' spectrum is because it was not solely one variable that influenced what nurses felt was acceptable, or not, for older persons with dementia, living in a nursing home to do. How the nursing team believed and decided that a form of sensuous-sexual expression was acceptable or unacceptable took shape the following ways: (1) who the expression was towards or what relationship was between two persons that were showing signs of affection with one another; (2) how the person was expressing their sexuality and what were they doing with their body; (3) where the expression took place and (4) how often the person expressed their sensuous-sexuality.

It is an important point to highlight that when the nursing team participants were speaking to me about their experiences of sensuous-sexual expression, this was for many the first time that they have had a conversation about the topic. The nature of the majority of the conversations I had with the participants, ended up being not only an opportunity to speak about their experiences, but a place where they initially realised some of the assumptions they hold about older person's sexuality. While they were sharing their stories of what expressions they had experienced and what was challenging and memorable for them, it appeared that the participants started to think deeper about their own values and beliefs, and where they came from. Many of the participants spoke about how they believe that sexual desire is a part of human nature and a meaningful aspect of life. Therefore, this framework

highlights that it is crucial for nurses to have dialogues and reflect on their own values and beliefs about sensuous-sexual expression and what this may mean for the older persons they are providing care for.

Enabling Learning and Practice Development

Enabling nurses to learn and to consider improving practice in the care home has also come out as a significant finding of this research in relation to sensuous-sexual expression. This was vivid to me when reflecting on the experiences of the nursing team. Sensuous-sexual expression usually only came to the nurses' attention when there were problems or concerns, thus highlighting that sensuous-sexual expression is positioned within a behaviouristic and unnatural view, rather than part of embodied sensuousness. The nursing home was viewed as a place for comfort and protection for older persons, especially those living with dementia. If an older person living with dementia has complex care needs, especially with needs around decision making and judgment, then sensuous-sexual expression was seen as something that was harmful to the person or others by the nursing team participants. Allowing sensuous-sexual expression to continue was not adhering to what is considered as 'good practice'. It became clear that the participants seen expressing sensuousness, especially in a sexual way as a threat to the protective environment the nursing home aims to provide for persons living with dementia.

The nursing team felt unclear and uncertain about the meaning of sensuous-sexual expression for persons living with dementia. Further, the appreciation of the sensuous body and sensuousness was absent. Nurses were able to describe situations of sexual expression vividly, and interpret bodily expressions as sexual, but were very unsure about what meaning or need lies behind each expression. Sensuous-sexual expression was not considered something to discuss or to develop appropriate care responses unless it became an 'issue' that needed escalated to the senior nurse, nursing home manager or general practitioner. By participating in this research, the participants wondered if there was a genuine desire behind the way the person expressed themselves, or if they said a sexual comment. Nurses do not know, or attempt to find out, what the resident is feeling and if they are

experiencing any sexual desires or feelings and perhaps an unmet need. The nurses were wanting some form of answers or guide for how to respond to specific situations of sensuous-sexual expression. This highlights the need for continuous dialogue, learning and development when it comes to sensuous-sexual expression in persons living with dementia.

Nevertheless, this research has exposed that education is not only needed to help nurses respond to moments of sexual expression in the 'there and then' of the moment. There are much deeper topics to be explored and potentially critical conversations to be had. By just creating the space for nurses to open up the conversation and for them to engage in a dialogue with another, the participants were starting to consider taken for granted assumptions more deeply and they started challenging their own practices. This was the first time for many nurses to engage in conversations around sexuality and older persons, including persons living with dementia, and there was evidence of buried values and assumptions being brought to the surface during these conversations, which is an important finding for this research. There also needs to be a sensuous presence within nursing and healthcare education to help nurses have a fuller understanding of expressing sensuousness and how sensuous knowledge can get us closer to understanding the values and beliefs of the person living with dementia. A culture where continuous learning and practice development is welcomed and encouraged will support nurses to care for persons living with dementia to continue and express who they are as sexual-sensuous beings.

Creating an Appropriate Environment

For older couples who sought intimacy with another, it was considered acceptable if their displays of affection took place within a private area of the home, which is only one of their bedrooms. This meant that it was 'out of sight, out of mind' for the nurses and they did not feel the need to intervene if the person with dementia was in their private rooms. Perhaps this was not just out of sight from the nurses but also other residents and visitors as many areas of the nursing home is seen as a public space, unlike a private home. There was a clear belief that certain moments

of expressing sensuousness were acceptable if the expression was concealed in the person's private space such as their own bedroom within the home or their bathroom.

This research also highlighted that the lack of privacy is a concern when thinking about expressing sensuous-sexuality and imagining the possibility of sharing sexual intimacy with a partner. Nursing homes tend to be public places where residents live their private lives (Young et al. 2012). The divide between public and private places can be problematic for persons living in long-term care settings, as privacy can often be difficult to find. The concept of privacy is indeed not a new concept, but this is the first-time persons living with dementia have spoken about their concerns with privacy in relation to their sensuous-sexual expression. Therefore, nursing homes need to consider how they can facilitate space and privacy for the older persons living in the home so that they have the inopportunity to share intimate moments with a partner, or express their sensuous-sexuality in whatever way they choose.

Most of us have very specific ideas of what we can do in the privacy of our own homes. Although we would not argue that we hope resident's 'feel' at home, 'homey' or 'like home', and that they are comfortable and relaxed and feel able to be themselves, we need to take care that we do not add to a confused idea about a nursing home environment literally being 'my home'. There are many things that are not like 'your own home', including many strangers living together, lots of other strangers telling you what to do, and even more strangers monitoring and regulating 'your home'. How you sleep and with whom, or no one, is often decided for the person, similar to what a person wears or does in bed, or on the sofa in front of the television. Living with dementia in a community environment that is clearly not home, but supposed to be home, can add to and create confusion about expressions not being shared in public and sometimes not even in private. It is important for persons living with dementia, to feel that they have the opportunity to have time and space for privacy in the environment that they are living in.

Closely linked with facilitating space and privacy for older persons to express their sensuous-sexuality and be intimate with a partner is the physical environment of the nursing home. The physical environment gave residents the impression that there is not the space to express sexuality. Many residents who are living in a nursing home will have most likely been used to sleeping in a double bed for many years and will have been comforted by being with someone they have an intimate bond with. However, residents are often sleeping in single beds as single beds are often more convenient for staff to provide care. Nevertheless, this provides a barrier for the person to lie down and sleep with a partner. The physical environment can often give out messages to older persons living with dementia, that a nursing home is not the place for sensuous-sexual expression. Thus, it is important that nursing home staff to consider the physical environment of the home to whether it is supportive (or not) of ensuring a person has the ability to comfortably spend time with a partner in their own private space.

Creating Space for Conversations between Nurses and Older Persons.

This research showed that older persons living with dementia enjoyed speaking about sex, intimacy and relationships. Prior to researching with the participants who were living with dementia, I assumed that it would take many conversations to gain some understanding around their personal experiences of sexual expression. This proved not to be the case. The older persons living with dementia presented themselves and showed interest to talk to me about what is important to them in regards to sexual expression and their sexual relationships. What was important was creating the space for older persons living with dementia to feel comfortable in sharing their perspectives and life experiences.

It is important as part of the nursing home culture, to create space and opportunities for the older persons to have conversations around sensuous-sexual expression. Building up relationships and 'being with' the person is crucial aspects in understanding the significance of sensuous-sexual expression to the older person living with dementia. Creating time and space for older persons living with dementia allows them to share their story and navigate where how they would like

the conversation to develop and how they would like it to take shape. This requires time and effort from the nurse to establish a person-centred relationship and to be willing to listen to the person and value who they are as a sensuous-sexual beings. The conditions need to be created to be able to understand how the person living with dementia is feeling, what their values are and how significant their sensuous-sexuality is to them.

Implications and Recommendations for Practice, Research and Education

Up to this point, I have described the new Sensuous-Sexual Expression Framework for persons living with dementia. In this section, I am going to address the implications for clinical nursing practice, research and education, which has emerged from the findings of this study. An important part of any PhD research in nursing, is how the findings are going to make a difference to nursing as a profession (Curtis et al. 2017) and contribute to human flourishing. Therefore, I am now going to take the findings and the main discussion points and show how there is potential for change and development. *Table 7* shows a summary of the implications for practice, research and education, with the view that policy is embedded within practice, research and education.

Practice

The findings from this research have introduced some implications for nursing practice. Despite the importance of sensuous-sexual expression to wellbeing and quality of life, this aspects of person with dementia's quality of life has received inadequate professional attention. If we are to advance thoughts and practice on sensuous-sexual expression in persons living with dementia, it is important for healthcare professionals to familiarise themselves with the sexual and intimacy topics encountered by older persons. It is important for anyone working with older persons living with dementia to examine their own values and beliefs with this 'taboo' topic and to ensure that they are open and comfortable to consultative discussions when appropriate. Developing awareness will depend as much on care providers and the general public taking stock of how their assumptions about who

counts as sexual and what counts as sex in relation to diverse older persons to avoid the pitfalls of a homogenising, one-size-fits-all approach to meeting the sensuous-sexuality needs of the person living with dementia.

Older persons living with dementia will benefit from sensitive conversations around sensuous-sexual expression to avoid concealing any sexual and intimacy concerns, embarrassment and to ensure that deep-rooted cultural issues are accepted and addressed. There is a need for a more positive perceptions of older person's sexuality, recognising the diversity of late-life sexual and intimate desires and legitimising other ways persons living with dementia can express this. Persons living with dementia also need to be included in conversations surrounding sensuous-sexual expression. The participants in this study felt that sexuality was not a nursing care issue that they should burden staff with. However, the participants expressed how much they enjoyed speaking about their sensuous-sexual expression as part of this research.

There is a need to embrace new understandings of sensuous-sexual expression in persons living with dementia that moves away from the tired and worn-out cultural norms that situate older persons as asexual. For persons living with dementia, to add cognitive decline on top of ageist stereotypes, has given professionals and academics the beliefs that sensuous-sexual expression is unnatural, strange and challenging. Nurses working in nursing and care homes need to have a fuller, and more realistic understanding of sensuous-sexual expression, and the Sensuous-Sexual Expression Framework has the potential to do just this. The Sensuous-Sexual Expression Framework demonstrates that sexuality is embodied, and therefore, does not 'disappear' or get forgotten about with age or living with a cognitive impairment. Older persons living with dementia, who are residing in nursing and care homes, experience sexual desires and long for intimate relationship. However, the perception from healthcare professionals view sexual expression as behaviouristic and a result of a dementia diagnosis. The Sensuous-Sexual Expression Framework has the potential to be a foundation where this new understanding can emerge from.

There also needs to be a promotion of acceptance, dignity and privacy for all residents to enable sensuous-sexual expression. There is a clear demand to develop person-centred care practices for nurses to incorporate sensuous-sexual expression as part of day-to-day care. A potential way to move forward with this is through a practice development methodology. The development of person-centred cultures cannot be achieved through a focus on implementing solutions that address particular aspects of a system ineffectiveness (McCormack et al. 2017). Rather, practice development looks at address embedded patterns in the workplace. To bring about fundamental change in complex cultures requires the recognition of patterns that drive thinking and behaviour (Plsek 2001). Patterns are associated with distinctive behaviour norms that manifest specific value, beliefs, and assumptions within a workplace (McCormack et al. 2017). This research has emphasis that the topic of sensuous-sexual expression in persons living with dementia is a victim of these distinctive behaviour norms, that need explored and challenged.

Research

It is vital that the voices of persons living with dementia are included in research and as co-producers of research about their lives as one key method of influencing practice, research and education. This research has given the opportunity of four persons with dementia, living in the same nursing home, an opportunity to share their lived experiences of sensuous-sexual expression. This study is a significant progress in dementia research, given the sensitivity of the topic and including persons who are often excluded from research or viewed as 'hard to reach' (Field 2019), as they are regarded by certain individuals as not having capacity. However, this should just be the beginning. There needs to be more research that captures the voices of persons living with dementia to get a strong body of knowledge.

Further research is needed to discover the use and applicability that the Sensuous-Sexual Expression Framework has for developing and improving care home practice. The framework has potential to evolve and develop practice and increase conversations around sensuous-sexual expression between nurses and older

persons with dementia. More research is needed to support nurses to use the Sensuous-Sexual Expression Framework in practice and connect with persons living with dementia. There also needs to be research that included older persons living with dementia in care home settings, to discover how they relate to the framework and how it can help support them living in a care home setting.

To the best of my knowledge, this research is the first to include persons living with dementia in a nursing home in the UK to talk about sensuous-sexual expression. I have found no research from anywhere in the world, that has included persons living with dementia who have a AWI certificate in place, and thus considered as not being able to give informed consent. This research should be viewed as a starting point and used as an example of how we can include more inclusive of persons living with dementia, no matter what stage of dementia they are experiencing. Hearing their voices within research needs to become the norm, not the abnormal. This research has developed rigorous and person-centred methods in which so called 'sensitive topics' can be explored with persons living with dementia and/or adults with incapacity.

This research topic and methods do not have to be confined for nursing home settings. There is a substantive gap in knowledge regarding sensuous-sexual expression in persons living with dementia in acute care settings and how nurses perceive and respond to sexual expression in environment which is very different from a nursing home. Nurses in acute setting, have found it difficult to provide care for individuals living with dementia, particularly if the care giving is for a prolonged period of time. If, as the literature suggests, nurses find essential communication and personal care challenging then it seems highly likely that sexual needs are not going to be addressed using the same methodological principles, this topic can be explored in a wide range of settings.

The persons living with dementia in this study were from a similar demographic background in that they were white Scottish. The persons living with dementia who volunteered to participate in this heterosexual and discussed having sexual and

intimate desires towards persons of different sex. Knowledge needs to be developed around sensuous-sexual expression and diversity. Therefore, this research should open a pathway for future research which actively seeks to include persons from a range of backgrounds, ethnic origins and persons from the LGBTQ+ community. MacGabhann (2015) argues that it is extremely unlikely that older persons who are lesbian, gay, bisexual or transgendered will be considered sexually active from a nursing point of view (MacGabhann 2015). Doll (2013) suggests that nursing home staff attitudes generally to not acknowledge persons sexual orientation, especially if they identify themselves as lesbian, gay, bisexual or otherwise, so this needs to be an area of future research.

Education

Many of the nursing team participants spoke about the lack of education and guidance when it comes to sensuous-sexual expression in persons living in a nursing home. There was a strong consensus that nurses needed and wanted some educational sessions about later life sexuality and to explore the minefield that surrounds dementia and sexual needs. Therefore, there is a need for awareness-raising, educational sessions available for nursing and care homes to help them develop their thinking about knowledge on sensuous-sexual expression. Some participants in this research, believed that having a conversation about the topic was a useful starting point to consider ideas to consider and ways to move forward, along with highlighting some concerns the nurses had. This demonstrates that interactive and social learning sessions or workshops could have the potential to be a useful educational tool for nurses. A couple of the participants also spoke about the fact that they were never 'taught' about how to deal with any sexuality issues in their training programme. This highlights that there is a need for nurse academics to pay more attention to sexuality and wellbeing and how a nurse's role could offer the right support and guidance for persons who they provide care for.

Conclusion

In this chapter, I have attempted to ensure that my interpretations remain situated in the phenomenon and the lived experiences of sensuous-sexual expression from the participants in this research. I have used the lived experience of sensuous-sexual expression from the participants and developed Sensuous Framework, presented in Chapter Four, to create the Sensuous-Sexual Expression Framework. This chapter has described the Sensuous-Sexual Expression Framework in detail and how it can be used to inform nursing care home practice. To conclude this chapter, I have offered a selection of implications that will be beneficial in the development of practice, research and education. What follows is the final concluding chapter of the thesis, where I provide a summary of the research, discuss its limitations and present my dissemination and impact plan.

Table 7: Summary of Implications for Practice, Research and Education

Summary of Implications		
Practice	Research	Education
<ul style="list-style-type: none"> • A need to embrace a new understanding of sensuous-sexual expression in persons living with dementia that embraces emotions, desires and senses. • Acceptance and acknowledgment that older people with dementia have a need for intimacy, love and sensuous-sexual expression. • A need to include more persons living with dementia in discussions around sensuous-sexual expression and intimate relationships. • A need to support and mentor nursing and care staff in becoming confident practitioners regarding sensuous-sexual expression and intimacy needs. • Practice development methods to develop person-centred care practices regarding sensuous-sexual expression for nursing homes. • Promoting a culture of acceptance, dignity and privacy for all residents is 	<ul style="list-style-type: none"> • A need for more research on sensuous-sexual expression which is inclusive of persons living with dementia. • Test out the applicability of the Sensuous-Sexual Expression Framework in clinical practice. • Further use of the sensuous methodology which has explores the lived experiences of sensuous-sexual expression in a person-centred way and considers the sensuous knowledge of all participants and the researcher. • A need for further research using rigorous and person-centred methods to explore with is regarded as sensitive topics with persons living with dementia who have an Adults with Incapacity (AWI) certificate. • An exploration of sexual expression in acute care settings and how nurses experience this phenomenon in hospital. • Future research exploring sensuous-sexual expression and diversity, e.g. how 	<ul style="list-style-type: none"> • Education and awareness-raising for nurses and care workers in nursing homes on sensuous-sexual expression for persons living with dementia. • Increased educational discussions and material about older age sexuality in general. • More attention paid to sexuality, sensuousness and wellbeing in undergraduate and post-graduate nursing programmes.

important for supporting sensuous-sexual expression.	sensuous-sexual expression is perceived in various ethnic cultures and LGBTQ+ communities.	
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Chapter Ten: Conclusion

Introduction

In this final chapter of the thesis, I bring this PhD journey to close for the time being. This chapter will start by discussing some of the strategies I have used to strengthen this research, focusing from a person-centred perspective. I discuss the how the use of thick descriptions, meaningful engagement with participants, having a supportive and critical relationship with my supervisors, and my reflective and reflexive skills, have enhanced the rigour of this research. Following this, I also aim to examine the study's limitations and the challenges that I was faced with during the course of this research. I then think forward and describe my dissemination and impact plan, and how I envisage this research evolving. To conclude this chapter, I provide an overall summary of this research, before bringing closure to this thesis.

Strengths of the Research

The use of thick descriptions in interpretative research help us to understand the meaning underpinning a situation or a person's experience (Shenton 2004). Without detailed rich descriptions, the finer details that explain how a certain phenomenon is experienced, could potentially be lost. Thick descriptions assist the reader with their understanding of a situation. A thick qualitative analysis both picks up finer details (nuances) and interprets what meaning they have for a situation (van Manen 2014). Therefore, the use of thick descriptions when describing the participant's experiences of sensuous-sexual expression, has been an important strength in this phenomenological inquiry. Enriched descriptions are an important provision as it helps to convey the actual situations that have been investigated and, to an extent, the contexts that surround them (Shenton 2004). Without this insight, it is difficult for the reader to determine the extent to which the overall findings 'ring true' (Shenton 2004, p. 69). By adding several participants quotations, or 'gems' within the phenomenological text, I have strengthened the rigour in my interpretations as they have enhanced the descriptions. In other words, this process has encouraged

the analysis to keep 'to the heart' of the participant's experience, which is an important principle for person-centred research (Davidson et al. 2017). When the contextual description is rich and the analytical language is comprehensive enough to enable readers to understand the processes and interactions involved in the context, it can make the research 'become alive' to the readers. Additionally, the use of thick description allows readers to be able to understand the experiences of the participants, with some sense of the mood, feeling, language, and the context. This enhances the authentic nature of the research (van Manen 2014).

Rigour was heightened through the meaningful engagement I had with the research setting and the participants. The process of building trust with the participants, prior to data collection starting, was a significant factor in exploring the phenomena of sexual expression. Building trust with participants increased the likelihood of participants providing honest and rich information, without feeling that they are being judged or scrutinised. It also made the research process an enjoyable experience for both the participants and me as the researcher. Spending time with the participants prior to collecting data from them, allowed a two-way reciprocal relationship to develop, in which they got to know me as a person as well as me finding out about who they are and what experiences were meaningful for them. I felt this was an important element of the research, as it helped that participants give very open and honest accounts of their experiences and what was being said in the recorded conversations were accurate representations of the participant's experiences.

Having frequent supervision and debriefing sessions with my supervisors was a crucial factor in this process. Through discussions with my supervisors, I was able to share my progress and receive feedback that was based on high challenge and high support (Titchen et al. 2017; Dewing et al 2014). From day one of this PhD, I embraced supervision sessions that was supportive and I was encouraged to celebrate various achievements along the way. Yet there was also a culture where challenge was welcomed, which was recorded in my supervisory learning contract.

Such collaborative sessions were used to challenge certain assumption that were possibly being made, gain a wider perspective, to discuss alternative approaches and draw attention to flaws in the proposed course of action. The sessions also provided a sounding board for me to test my developing ideas and interpretations and getting feedback from my supervisors helped me recognise my own biases and preferences. My supervisors, who have extensive experience in qualitative research procedures reviewed and offered me feedback of my analysis of the raw data, and listened to any concerns I had.

In addition to having an established peer review process, the researcher should evaluate and reflect on the project as it develops (Titchen et al. 2017; Shenton 2004). Reflection and evaluation have been a continuous process through this research when monitoring the progress of this research. Reflection and reflexivity have also been a vital skill when thinking about my knowledge and skill development as an early career researcher. This was recorded throughout the Researcher Enhancement and Development (READ) course I was enrolled on, which I have successfully passed and received a doctoral certificate in. The commentary can play a key role in monitoring of the researcher's own developing ideas and interpretations. Throughout data collection, analysis, interpretation and writing up, I critically reflected on my own preconceptions and monitored the relationships I develop with participants and my own reactions to participants' accounts and actions.

Possible Limitations of research

In this section, I recognise the limitations of the study. I was able to remain open to the idea that any obstacles I encountered through this research are part of the meaningful pathway of research (Collins and Cooper 2014). Therefore, although limitations need to be made clear, I did not feel they limited the research too significantly.

The Interpretative Nature of the Research

A potentially limiting aspect of this research for some researchers and scholars, is its interpretive stance. I believe that interpretation is essentially part of all experience and has the potential to lead to exciting new insights and knowledge, I am aware that others will not agree with this, including those with a more positivist worldview (Crotty 1998). Even amongst phenomenologists there is disagreement about this. Phenomenological research characteristically starts with concrete, rich descriptions of lived experiences, set down in everyday language and avoiding abstract intellectual generalisation (Finlay 2009). The researcher proceeds by reflectively analysing these descriptions, individually first and then offering a synthesised account by identifying and presenting the essence of the phenomenon. Additionally, the researcher aims to go beyond surface expressions or explicit meanings to expose more concealed and hidden meanings. It is this process of 'reading between the lines' which has generated uncertainty amongst phenomenologists (Finlay 2009, p. 10.).

If I had chosen to adopt a descriptive phenomenological methodology, I would have had to have stayed close to the data in all its richness and complexity yet restrict myself to 'making assertions which are supported by intuitive validations' (Giorgi 1985, p. 9). In contrast, I have positioned myself as embedded throughout the research process, just as interpretation is embedded in our everyday lives (Merleau-Ponty 1962; van Manen 1990). As Hammersley and Atkinson (2019) note, existentially, the researcher is part of the world that is studied. However, I need to be conscious of the fact that others may have interpreted the data in various ways, just like persons interpret similar experiences differently. Another approaching the same topic, in the same setting and with the same participants, may have had different conversations with the participants, interpreted what was said and felt differently and findings would have been different (Todres 2007). Nevertheless, this process has the ability for the reader themselves to re-interpret the findings in ways that are meaningful to them. The interpretative nature also means that one must come to terms with the fact that there can never be a completed picture. This

research is therefore limited because, unlike some other methodologies, it can never be considered as the final word on its subject, there will always be more that could have been said, or written in a different way, or said with a changed emphasis to provide an alternative perspective.

Context Specific

This study took place in one nursing home setting, so it is important to acknowledge the limitation of its scope for transferability. The setting in which I conducted this research is a particular organisational context where the team has their own history, relationships and ways to relate with each other, as well as with the organisational environment. Whilst the participant's included in this research have brought a fascinating and meaningful contribution of their lived experiences to the research, it is important to remember that every person is unique, and different participants would have had their own individual stories to share, which would have influenced the research differently. While the outcomes of this research are context and participant specific, I am confident that the new knowledge and insight from this research is significant and relatable to others.

Being an Outsider

In this research design, I was positioned as an 'outsider' researcher as I had no knowledge of the practice context or any relationship prior to the commencement of the research. Being an outsider researcher can be useful in unearthing embodied or tacit cultural phenomenon that are not usually visible to persons embedded in a practice context (Eide and Cardiff 2017). However, outsider researchers need to pay attention to their awareness of, and responsiveness to, practice context in order to build psychologically safe, facilitative relationships with practitioners, such that they can share their practice (Eide and Cardiff 2017; Jacobs et al. 2017). In this study design, greater attention needed to be paid to the researcher's position and the conditions that needed to be nurtured in order to develop dialogue. Nonetheless, it has been suggested that outsider researchers have an important role to play in practice enquiry and practice development and should become insiders that enable

practitioners to explore and transform their own practice and undertake research and development in a problem area (Fish and Coles 1998; Jacobs et al. 2017). However, even with such distance from being an outsider, I was able to feel some closeness through the relationships I developed through spending time in the nursing home and with the participants of the research.

COVID-19

The research fieldwork was initially planned to take place over six months, from January – June 2020. However, in March 2020, because of the coronavirus pandemic the UK government announced a national lockdown for public safety (GOV.UK 2020). From the 16th March 2020, only essential key workers could continue to work in their work environment. This meant that I was unable to carry on with my research visits in the nursing home and data collection had to stop abruptly. Every nursing team participant who expressed their desire to be included in the research had their opportunity to participate in observations and conversational interviews. Unfortunately, I was unable to have conversations with two persons living with dementia who volunteered to participate in the research. I considered the possibility of having virtual conversations with the two persons living with dementia. However, I had not spent near as much time getting to know each other, building up a trusting relationship and co-creating their research plan with them. Therefore, I felt that if I offered virtual conversations with the two potential participants, they would not have had the research experience they deserved, and I would not be adhering to my methodological principles.

It could be argued that I managed to get a large percentage of the potential data that I 'needed' to progress to a deeper level of analysis and get findings. However, the way this research ended was certainly not what I 'wanted' or anticipated. If it were not for COVID-19, I planned to continue to visit the nursing home until June 2020, where I would still have been engaging with the participants throughout the analysis process. I originally planned that I would present the findings back to the participants and offer them opportunities to give me feedback, whether this was in workshop style groups or individually. However, because of the circumstances this

was not possible. Nevertheless, once restrictions ease my aim is to go back to the nursing home, present the findings and offer some educational workshop sessions.

Dissemination and Pathway to Impact

Creating a sound dissemination strategy for a research project will lead to increased awareness of the research and, therefore, maximise the impact that the research can have in improving the health outcomes of the persons that will benefit from it. The UK based Vitae Researcher Development Framework (RDF) (Vitae 2011) identifies knowledge, attributes and behaviours that doctoral researchers should demonstrate in all areas of research. The attributes related to research dissemination and impact are particularly useful in guiding identification of principles and plans. The Vitae Framework (2011) suggests that researchers need to demonstrate professional integrity and honesty in research dissemination and engagement.

Dissemination and engagement are something that has been viewed as an ongoing process through this research, and not just waiting to present the findings at the very end. From the beginning, I have been encouraged to develop my dissemination skills and raise awareness about the ongoing research. Since 2017 I have been showcasing the developments of this research. I have presented at conferences both locally (NHS Lothian nursing, midwifery, allied health professionals, psychology, pharmacy and health care science (NMAHPPS) research conference, March 2018), nationally (Alzheimer's Scotland conference, June 2017 and June 2018; Helping all persons to flourish: Interdisciplinary and creative practices in care homes conference, September 2019); and internationally (Alzheimer's Europe, October 2020). I have also facilitated interactive workshops session around sexual expression in persons living with dementia, particularly focusing on sexual expression within a care home context. Again, I have had experiences at facilitating educational workshops both locally (Queen Margaret University, Scotland), nationally (South Devon, England) and internationally (Donegal and Sligo, Ireland;

New South Wales, Australia). This has helped give me a broader understanding of the national and international context of the research (Vitae Framework 2011).

It is also important to reach out to the general public and have a diverse way of getting your 'out there', and not solely to academics in your specific field (Vitae 2011). During my funded visit to Australia, I was invited to be interviewed by a local radio station in New South Wales, ABC Illawarra. The producers of the radio station saw the advertisement for my presentation on sexual expression in persons living with dementia and wanted to hear more about my research topic. To my astonishment, approximately 31,400 listeners were tuned in for my conversation on sexual expression in persons living with dementia. I imagine this has got members of the public speaking about a topic that is considered taboo and sparked a lot of conversations. Talking about older persons and sexual expression is certainly not your typical breakfast radio show topic, but I was delighted that the radio producers saw that this was a topic of immense value and wanted to open up discussions about this.

For researchers to understand the process of publication and produce publishable material in addition to being able to identify a diverse range of publication outlets, is viewed as a crucial part of being a researcher (Vitae 2011). In 2017, I published a literature review on sexual expression in persons living with dementia in the All Ireland Gerontological Nursing Association journal (Rennie et al. 2017). I consider it is important to disseminate the findings from this research. This will be to share its methodology, data and outcomes, and also to stimulate further discussion and inspire practitioners, researchers and educators to use this work for their own development. My initial plan for publication is outlined below:

- To write an article presenting an overview of the study including its methodology and findings.
- To report the findings of this research and its implications for person-centred practice.

- To write an article focussed on the methodology and its suitability for including persons living with dementia who have an AWI certificate in place.
- Publish an article describing the discrepancy between the BPSD model and person-centred practice.
- To write an article describing the development and the potential of the Sensuous Framework.

Finally, being intentional about the audience that research sharing and impact efforts are carried out with is a significant consideration for this research.

Researchers currently live in an increasingly networked world in which academic collaborations are growing and disciplinary diversity (Reed 2018). Additionally, researchers are under more pressure today than ever before to demonstrate the economic and social benefits, or 'impact', of their work and demonstrate tangible impacts from their work (Reed 2018). Therefore, post-doctoral, I plan to continue to disseminate the findings and implications from this study, but also to create or sustain relationships with key stakeholders who would be interested to measure the impact of this research. I want to provide evidence that could be used to inform nursing home practice regarding sexual expression in persons living with dementia and continue to engage with stakeholders to help turn theory into practice. Key stakeholders could be nursing homeowners and managers, care directors, nursing and care staff in nursing homes, care home educators, nurse academics and policymakers. Overall, in addition to dissemination, it is important to identify and maintain engagement practice and support practice development processes.

Conclusion

There is a need for more positive perceptions of older person's sensuousness, including recognising the diversity of late-life sexual desires and legitimising other ways in which persons living with dementia express their embodied sensuous-sexuality. Researching this topic of sensuous-sexual expression has engendered in me a real sense of compassion, empathy and consideration for both residents and

care workers in this ambiguous and difficult area. It has helped me to be more reflexive in my own work practice and has helped to further my understanding of the subject.

Emerging from this research is a new framework, the Sensuous-Sexual Expression Framework, which can serve as a heuristic guide for nurses, other healthcare practitioners, researchers and academics when thinking about sensuous-sexual expressions and persons living with dementia. The findings from this research can show that sensuous-sexual expression stems from our embodied emotions, desires and senses, which does not diminish, although may take a new approach, as persons get older and are living with dementia. For the nurses, they currently do not see sexual expression considering a person's sensuousness, as they see sexual expression as something to manage. The data reflects this very much rather than how seeing sexual expression as part of a person's sensuousness. This is shown in their data because of the way they have constructed this in practice and culturally. The Sensuous-Sexual Expression Framework can offer a new way in which sexual expression is perceived and understood for nurses caring for persons living with dementia. There is potential for sensuous perspective to not only re-theorise sexual expression, but also as a guide to view other personal expressions which is dominated by the BPSD worldview. I plan to not only continue with research on the topic of sexual expression but see how much sensuousness can be a valuable theoretical background for understanding all expressions from persons living with dementia.

The study demonstrates that there are persons with dementia who are able and want to contribute to research their nursing home experience if appropriate methods are used to support active and meaningful participation. This is the first study in the UK where persons living with dementia were provided opportunities to share their experiences about expressing their sexuality in nursing homes. This study offers a unique contribution to the knowledge base in the field of dementia care in nursing homes by beginning to use first person voices of persons with dementia using person-centred research methods.

This research has further ignited my ambitions of being an early career research and create a plan for my future practice as a person-centred researcher. With this in mind, I hope to move forward with research using similar methodological principles, with added action principles where practice can develop and change for the better. This research focus, underpinned by the Sensuous-Sexual Expression Framework which was developed in this research, will create opportunities to enhance the knowledge on sensuous-sexual expression and create opportunities for developing practice in relation to sensuous-sexual expression in person living with dementia in a nursing home context.

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Appendix 1: A Challenge on Behavioural and Psychological Symptoms of Dementia (BPSD) and Exploring Sexual Expression in Persons Living with Dementia - A Poem by Karen Rennie

*Today I want to share with you,
My findings from my literature review.
In fact, this poem will tell you the story of two,
Two reviews that is neither meta-analysis or systematic,
But, nevertheless could be just as fantastic.
A critical review methodology was chosen
To uncover the knowledge that was frozen
Once that knowledge is unfrozen
And a philosophical framework is chosen.
We can synthesise and arrive at new insights.
To a way of providing dementia care that is bright.
The PRISMA tool was used as a guide,
To keep track of all the literature and resources I needed to find.
To analyse a wide range of sources
To get a conclusion, or a model in which all of society endorses.
So what am I looking at to critique?
That will make my research stand out and be unique
My PhD is looking at persons with dementia and sexuality
With the aim of looking at this topic with some normality.
But how do we view persons with dementia and sex?
I think we need to look back before we can shape what's coming next.
We need to re-evaluate the BPSD framework*

*Without some healthcare professionals going berserk.
Through many months of scavenging through literature old and new.
The number of sources included reached forty-two.
So let me take you back to 1996
When many psychiatrists got together to work out a way to fix,
To fix what they thought was a mental health disease,
Their patient's behaviours and anything else they pleased.
Before dementia was pathologically understood
The group in the US probably tried the best they could.
With changes to movement, judgement and other symptoms unknown.
Psychiatry felt that dementia was theirs to own.
They looked at behaviours as a symptom of dementia or a sign.
But where was their knowledge baseline?
60 'experts' gathered to discuss what is BPSD and how it should move forward.
Firstly, who was classified as an expert?
Is it a doctor or someone who has made an academic effort?
Or is it someone who experiences dementia? Who lives with it every day?
Perhaps they didn't want their idea to sway...
So what did the group decide?
That we should put all emotions and feelings aside...
Assumptions based on the idea that the mind and body are detached.
That once your mind has gone, your life will be snatched.
According to the experts behavioural and psychological symptoms are an "integral"
part of the disease
So when there are changes to the brain, do all emotional responses freeze?
But, all symptoms of BPSD are apparently treatable
Therefore personal expressions are deemed as unnatural.*

In fact, this position classifies them as a sign of sickness.

And this viewpoint got me suspicious.

So where did the international psychogeriatrics association get their support?

That helped the healthcare policies and practices readily adopt...

Despite claiming that drugs is not the first port of call,

They called the need for drug therapy research, but that not all.

The conference where BPSD was created,

Was sponsored by a pharmaceutical company without being slated.

So what are these 'symptoms' of dementia?

What do they mean when they are talking about behaviours that are challenging?

Cohen-Mansfield and authors have clustered these in to 29 themes.

We're talking about 'fidgety behaviour', 'restlessness' or problems to sleep.

Along with making noises, complaining or always wanting to weep.

It could be screaming, cursing or hitting out.

Expressing your sexual needs or just saying 'nout.'

This is what happens when you get dementia

You get viewed as challenging and problematic.

Your thoughts and feeling...just static.

I now encourage you to think and reflect

On a time where your needs were not met.

A moment in life where you felt vulnerable, angry or nervous,

Situations of public speaking, or waiting on an NHS service.

Pacing the floors waiting on your teenage daughter coming home from a night out on the town,

Or have you ever felt alone with no one around?

How did you feel? How did you act?

What was your body telling you to do in order to react?

*Did you fidget or cry like me?
Or do you get angry and lash out to some degree?
When vulnerable, who amongst us needs to get some fresh air?
Or turns silent when they are feeling a pain that they cannot bare?
Why when it comes to emotions, do we try to hide?
What are we trying to protect - Is it our pride?
So what is the difference when it's someone living with dementia?
I may be able to say that I am okay,
Or if I can't, I would be able to say why I'm finding it hard to get through the day.
Whereas someone with dementia may not be able to articulate
Therefore, they are being made to wait, and wait, and wait...
So why am I not getting drugs?
Or therapeutic interventions such as music therapy or a clinical hug?
If I was to be assessed before speaking to you now,
I would also have BPSD and possibly a few raised eyebrows.
But because I can try to cover it up or talk about what's bothering me
You would lend me a hand or make me a cup of tea.
With someone living with dementia, it may just be harder to understand,
Therefore, research, which includes people with dementia, should be in high demand.
A parliamentary inquiry called for drugs which are prescribed for BPSD to be reduced
However, evidence tells us that antipsychotics are still being misused.
Research shows that BPSD often occurs when admitted to hospital,
But don't you get agitated going for surgery, even just a little?
Healthcare professional feel uncomfortable when responding to personal expressions
The poor effects and outcomes of the drugs puts this model in to question.*

There has been an increase in research calling for social interventions to 'manage' BPSD

Is this person-centred? Not to me...

I admit, that this is better than popping a pill

And understand that it comes from a place of good will.

Yet, I can see there are still some major cracks,

Potential for more despair and many setbacks.

Even if social activities are a step in the right direction,

They are still 'provided' on the perspective of BPSD and emotional disconnection.

We come from the perspective that views the person as a whole, that embraces personal choice and autonomy

Yet, BPSD still dominates how we view expressions that are bodily.

What we need is a direction away from BPSD or paradigm shift,

To a perspective, that values the body and emotions – values it like a gift.

Through viewing people with dementia within the lens of my chosen philosophers, Maurice Merleau-Ponty and Mark Johnson,

who I believe are pretty awesome,

We can see that emotions, senses and desires,

Help us to gain meaning, understand the world and aspires.

I propose a paradigm in which we embrace natural human feelings.

So how can we get going and start the proceedings?

We need ask people with dementia

Ask what do they think and let's hear their voices

To understand as healthcare professionals how to move forward and what are our choices.

So what does this mean for my PhD topic?

Well for older adults with dementia, they are usually prescribed an antipsychotic.

Especially when they express themselves sexually.

But, wait surely older people don't have sex...

Don't they just sit around and watch the telly?

How important is sex and intimacy?

For those who can't understand numbers or struggle with literacy.

Our society tends to believe that older people no longer have sexual needs or any desire.

But what I found was that intimacy was important,

Whether that meant some fun in the bedroom or a cuddle by the fire.

Dourado and colleagues explored this topic with 36 couples,

One of which had Alzheimer disease and yes they still all enjoyed cuddles.

64% of people with Alzheimer's disease reported regular sexual activity,

However, the author did little to increase validity.

Other studies showed that people with dementia engage in holding hands, kissing and intercourse

Others reflected on their previous relationships with some remorse.

For those who said their sexual aspect of their relationship had disappeared,

Feelings of sadness, anxiety, and low self-esteem were very clear.

Research showed that older people who had sex had higher levels of wellbeing

But, sometimes the dementia diagnosis is all that we are seeing.

These wishes are true for those living in a nursing home,

As studies have told me from London, Sydney, Tokyo and Rome.

Simpson found that residents missed being touched in an intimate way,

But there's little room and privacy for a partner to stay.

Cultural perspectives of people with dementia and sex were explored in U.S

To see whether the public support, encourage or suppress.

318 members of the public took part in a quantitative questionnaire

However, listening to some of the responses I could not bear.

Over 35% of responses stated that they were against people with dementia having an intimate relationship.

But do they think of the importance of companionship?

All they see is a vulnerable person,

I know it doesn't come from a bad place, they just don't want their situation to worsen.

Approximately a quarter of people that took part in this survey,

Says that for those who have dementia,

The mental capacity to experience love and closeness goes away.

"I just know when you lose your mind you don't know what you are doing. I mean it's just not right"

Says one of the participants in this study, but do they have true insight?

Usually if is a long term married couple, the nursing home will tolerate,

But what about a newly formed older couple who may want to go on a date?

Even though two studies looking at public perception of people with dementia and sex is not a lot to rely on,

It still tells me that there are ageist assumptions and sex and dementia is frowned upon.

However, the media has taken interest in bringing this subject to public attention.

Headlines in the BBC and the Telegraph, such as "the taboo of sex in care homes" and "over 65s would like more sex"

And so much more I could mention.

No doubt these headlines have sparked so much conversation.

So why do we not see research into this area develop in acceleration?

Healthcare professionals have rated sexual expression as the most difficult symptom of BPSD to 'manage'

Usually it is met with uncertainty and creates a lot of panic.

In 2004 and by using grounded theory,

Roach found that many nursing home staff respond to sexual expression negatively and with weary.

Perceptions were influenced by staff's own levels of discomfort

Alongside the ethos within the organisational culture.

In other studies, responses ranged from nurses perceptions on being open minded and understanding.

To perceptions that view it as an issue, and that people with dementia are demanding.

Many nurses felt uneasy and undereducated when discussing about older people and sexuality.

They voiced concerns about the lack of resources to assist and to change the mentality.

As nurses we can be very comfortable with a very sensitive matter,

Not a day goes by that we don't talk about bowels during our natter.

Yet, we seem to struggle to talk about sex even though it's for most, an important part of life.

And what people with dementia say and what happens in practice seems to be stuck in a strife.

All assessment tools that incorporate sexual expression, or as they put it, 'inappropriate sexual behaviours'.

Come from a BPSD perspective and believe pharmacology acts as a saviour.

Tucker suggests an approach for responding to sexual expression in the form of an algorithm,

First port of call is usually behavioural therapies, interventions or separation,

Before ultimately moving towards unnecessary medication.

Sexual expression was met with humour, avoidance or distraction

Staff were very unsure on the right course of action.

It was not only with people living with dementia, but older adults in general,

Which emphasises ageist stereotypes and views that caregivers should be parental.

Taking what the literature and evidence says,

There is a long way to go before sexual expression is viewed in a person-centred way.

All the evidence on sexual expression originates from long-term care settings,

But from my experience, nurses working in hospitals find this phenomena just as upsetting.

We need to understand the significance of sexual expression and what people with dementia are perceiving

What is important to them and how we can understand the underlying meaning.

There are two major assumptions that my critical reviews are trying to critique,

That the BPSD model, including sexual expression needs to be challenged,

And asking the question why have persons living with dementia not been allowed to speak.

Where we see the body as a source of emotions, desires and sense impression.

But not only as a thing in itself,

But that bodily emotions is our way of gaining meaning – getting to know our true self.

Appendix 2: Ethics Approval Letter



Queen Margaret University
EDINBURGH

Name: Karen Rennie
Status: PhD Candidate
Subject Area: Nursing
School: Health Sciences

Lucy Hinds
Quality Enhancement Officer
Queen Margaret University
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU

18 November 2019

Tel: 0131 474 0000
Email: researchethics@qmu.ac.uk

Dear Karen,

Ethical Approval – Sexual expression in persons living with dementia and impact

Thank you for submitting your application for ethical approval for consideration by the Research Ethics Panel. The Panel have reviewed your application and full ethical approval has been granted for your research, subject to the linking of your existing PVG certificate with a QMU record (indicated to you in previous correspondence). Please note that you cannot undertake any data collection until this has been completed and confirmed to researchethics@qmu.ac.uk.

One of the reviewers provided some feedback which is not connected to the ethical approval of the research but you may wish to consider:

- It is suggested that you consider clarifying the title and/or the research question. The Reviewer commented as follows: *'Is the primary subject of study the sexual expression in those living with dementia, or the impact of the sexual expression of those living with dementia on those who care for them (in a healthcare context)? In one instance, the researcher wishes to "find out how sexual expression effects nurses working in care home settings and to understand more about how sexual expression effects nursing care." But if this is the case, why is the researcher inviting "people with dementia to participate in this study and with their consent have conversations about their experiences of nursing care and explore how sexual expression weaves into bodily and other aspects of care"*

While I don't doubt they are intricately related, and that one has to be understood in relation to the other, I would have liked to see more clarity on the subject/object of study, and which the primary goal of the study is.'

A standard condition of this ethical approval is that you are required to notify the Panel, in advance, of any significant proposed deviation from the original protocol. Reports to the Committee are also required once the research is underway if there are any unexpected results or events that raise questions about the safety of the research

We would like to thank you for your co-operation and wish you well with your project.

Yours sincerely
Lucy Hinds
Secretary to the Research Ethics Panel

Queen Margaret University, Edinburgh, Scotland, EH21 6UU
Tel: +44(0)131 474 0000 Fax: +44(0)131 474 0001 www.qmu.ac.uk

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DIVISION OF GOVERNANCE AND QUALITY ENHANCEMENT
QUEEN MARGARET UNIVERSITY, EDINBURGH
MUSSELBURGH
EAST LOTHIAN EH21 6UU
TELEPHONE: 0131 474 0000

PhD Research Study:

“Sexual Expression in Persons Living with Dementia and Impact on Nursing Care in Nursing Home Settings”



My name is Karen Rennie and I am a full-time PhD Candidate at Queen Margaret University. I am a registered nurse and work in a nursing home in Edinburgh as a staff nurse.

My PhD topic is exploring ‘sexual expression in persons living with dementia and how this impacts on nursing care’. This research study will help us to learn more about sexual expression in persons living with dementia, and how it effects nurses working in nursing homes. The study is being carried out in Erskine Park Home.

I will be visiting and working in the nursing home in an honorary capacity. This will allow me to work closely with the nursing team and build up relationships with persons with dementia who are living in Erskine Park Home. During this time, I hope to have conversations with persons living with dementia and members of the nursing team about experiences of care. I will also be asking the nursing staff if I can conduct observations, where I will be observing how nursing staff interact with persons living with dementia.

If you have any questions or concerns or want to find out more about this study please do not hesitate to speak to me or the nursing home manager. You could also email me at krennie@qmu.ac.uk.

Thank you,

Karen



Queen Margaret University
EDINBURGH

Appendix 4: Information Sheet for Legal Representatives

Tuesday 10th September 2019
Version 1



Queen Margaret University
EDINBURGH

Information Sheet for Welfare Attorney/Welfare Guardian/Nearest Relative of People Living with Dementia

“Sexual Expression in Persons Living with Dementia and Impact on Nursing Care in Nursing Home Settings”

You are being invited to consider giving your permission for your relative/person you are consenting for to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve.

We would then ask that you put your own views about the research aside and to consider and take into account, the past and present wishes and feelings of your relative/person you are consenting for, had they been able to consent for themselves.

My name is Karen Rennie and I am a full-time PhD Candidate at Queen Margaret University within the Centre for Person-Centred Practice Research. I am a registered nurse and still contribute to clinical practice as a staff nurse. My PhD topic is exploring ‘sexual expression in persons living with dementia and how that impacts on nursing care’. As you are a welfare attorney/welfare guardian/nearest relative of someone who is living with dementia who is residing in this nursing home, I therefore invite your relative/person to take part in this study.

Before you decide whether or not to give consent for the inclusion of your relative/person, I want you to understand why this research is being done and what

it would involve for your relative/person. Please take time to read the following information. If you have any queries or questions before you make your decision, I would be very happy to have a discussion with you.

Research Summary

Research has shown that nurses find it particularly difficult to provide care for individuals with dementia and more so when 'inappropriate' or 'excessive' sexual expressions are evident. Therefore, this research aims to explore this in more depth in order to help improve care for persons living with dementia who express themselves sexually.

If, having read this leaflet, you are interested in the research, then we can arrange a meeting in the nursing home at a time that is most convenient for you. The purpose of this meeting is to discuss the study in more depth. **The researcher will go through this information leaflet with you and answer any questions you have.**

What is the purpose of this study?

The purpose of this study is to gain knowledge on the meaning of sexual expression in persons living with dementia and how it effects nurses working in nursing homes.

Why has my relative/person been asked to take part?

Your relative/person has been invited to join this study because I want to learn about their perspectives and experiences on their care has been and how they feel their sexuality and sexual expression is being supported by the nursing team while residing in the nursing home. This will help us to better understand how sexual expression is currently perceived by the person living with dementia and the nursing team and what responses/interventions are currently being used to respond to sexual expression by persons living with dementia.

Do I have to consent to my relative/person to take part?

No. It is up to you to decide whether or not you wish your relative/person to take part in the study. If you do wish for them to participate, we will ask you to sign a consent form. We would then ask that you put your own views about the research aside and to consider and take into account, the past and present wishes and feelings of your

ward/relative/person you are consenting for, had they been able to consent for themselves.

You are still free to withdraw your relative/person at any time without giving a reason. You can also choose to receive more information about the study and decide to provide consent for your relative/person to participate in the study at a later date.

What is the overall design/plan of the research?

I will be visiting and working in the home as a registered nurse in an honorary capacity. This will allow me to work closely with the nursing team throughout the study and build up relationships with nurses and persons with dementia who are living in the home. The total time I will be in the home will be between 2-4 months. During this time, I hope to have unstructured/conversations interviews with approximately 10 members of the nursing team semi-structured/conversational interviews, which aims to discover the experiences of sexual expression in persons living with dementia. I will also be asking the nursing staff if I can conduct participant observations, where I will be observing how nursing staff interact with persons living with dementia.

Following on from exploring nurses experiences of sexual expression in persons living with dementia, I will then seek to recruit persons living with dementia and inviting them to take part in conversational interviews to understand the meaning of sexual expression from their perspectives. This allows me to gain deeper insights into nursing care of persons living with dementia and to suggest and develop person-centred principles and guidance which will contribute to evidence base nursing.

What are the possible benefits of taking part?

Your relative/person may not get a direct benefit from taking part in this study. However, sometimes when people are asked to participate in research that involves asking them to talk about and share their experiences, it can help them to understand their situation and experiences better.

By participating in this research your relative/person will be helping us better understand the phenomenon of 'sexual expression' and how nurses can support and respond to sexual expression in ways that are sensitive, support the needs of

people living with dementia and provide high-quality person-centred care. They will also be contributing to publication on future nursing practice and dementia care in relation to sexual expression.

What are the possible disadvantages of taking part?

The topic of sexuality and sexual expression could be sensitive to people, thus having the potential to lead to feelings of stress or could be upsetting for people. Your relative/person may discuss a situation that they have found challenging and/or upsetting. Therefore, your relative/person will always have the opportunity to take a break from the conversation or to withdraw from the study completely.

Arrangements can also be made for your relative/person to speak to the researcher about what has upset them, or to speak to a consultant independent of your care, should they wish.

If your relative/person chooses to stop the conversations the researcher will ask them if they would like to participate or finish the conversation on another occasion, but this would be your relative/person choice. If you as the person's welfare attorney/welfare guardian/nearest relative believe that your relative/person is too distressed to continue participating in the study, you have a right to pause, stop or terminate their involvement in the research. Some people do find it helpful to have the opportunity to talk about their experiences even if this is hard at times. After each discussion all participants will be offered a follow-up consultation or a contact will be provided for additional support.

Will taking part in the study be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your relative's/person's privacy at every stage. Access to your relative/person personal information is for the purpose of this study only and is restricted to the researcher. The information collected from your relative/person, and about them, will be stored on a secure password-protected computer and in a locked filing cabinet. All information collected will be fully anonymised and no identifying details will ever be made public. With your consent, I may use quotes from your relative/person and other participants in the results of the study. The quotes but they will not be linked to your relative/person's name or identity.

The only exception where we may need to breach confidentiality is if during the interview information is shared that highlights issues of concern around risk to yourself or others, or poor practice. As a healthcare professional, I have a duty of care to raise issues of concern through appropriate channels in the organisation involved. This will be discussed with you and your relative/person.

Can I agree now and change my mind later?

Yes. It is possible to withdraw your relative/person from the study if you change your mind later on. If you choose to withdraw, we will ask you if any information that has been collected from your relative/person, and about them, can still be used in the results of the study. If you would prefer to withdraw all information collected it will be destroyed using confidential means and will not be used for research.

What will happen to the results of the study?

The results of the study will be written up for publication in journal articles and will be presented at national conferences and educational seminars. We will also report the findings to relevant expert panels and other stakeholders. You will not be identifiable in any reports or published results.

What happens when the study is finished?

At the end of this study the information collected from you and about you will be retained for five years. The permanent disposal of this data will then be arranged in line with current guidelines.

What if there is a problem?

If you have a concern about any aspect of this study please speak to the researcher or the independent advisor who will do their best to answer your questions.

Contact details of the researcher

Name of researcher: Karen Rennie

Address: PhD Candidate,
 Centre for Person-centred Practice Research
 Division of Nursing, School of Health Sciences
 Queen Margaret University, Edinburgh

EH21 6UU

Email / Telephone: krennie@gmu.ac.uk / 0131 474 0000

Contact details of the independent adviser

Name of adviser: Dr Fiona Kelly

Address: Lecturer, Division of Nursing, School of Health Sciences
Queen Margaret University
Queen Margaret University Drive
Musselburgh
East Lothian
EH21 6UU

Email / Telephone: fkelly1@gmu.ac.uk / 0131 474 0000

Who is overseeing the research?

This study is led by Queen Margaret University.

Dementia Helpline (24 hours)

0808 808 3000

Appendix 5: Consent Form for Legal Representatives

Tuesday 10th September 2019
Version 1



Queen Margaret University
EDINBURGH

Consent Form for Potential Participants: Welfare Attorney/Welfare Guardian/Nearest Relatives

“Sexual Expression in Person Living with Dementia and Impact on Nursing Care in Nursing Home Settings”

Please tick/initial boxes

I have read and understood the **Information Sheet for Welfare Attorney/Welfare Guardian/Nearest Relative of People Living with Dementia, version. 1, 10/09/19**, and this consent form. I have had an opportunity to ask questions about the participation.

I understand that my relative/ person I am consenting for's participation is voluntary and that I am free to withdraw my ward/relative/person I am consenting for at any time, without giving any reason and without my ward's/relative/person I am consenting for's medical care or legal rights being affected.

I agree to my relative/person I am consenting for taking part in the above study

I confirm that I am the Welfare Attorney or Welfare Guardian or Nearest Relative for:

Name of Person taking Consent:

Signature of researcher:

Date: _____

Appendix 6: Information Sheet for Persons Living with Dementia

Tuesday 10th September 2019
Version 2



Queen Margaret University
EDINBURGH

Information Sheet for Potential Participants: Persons living with Dementia

“Sexual Expression in Persons Living with Dementia and Impact on Nursing Care in Nursing Home Settings”

My name is Karen Rennie and I am a full-time PhD Candidate at Queen Margaret University within the Centre for Person-Centred Practice Research. I am a registered nurse and work in a nursing home in Edinburgh as a staff nurse. My PhD topic is exploring ‘sexual expression in persons living with dementia and how this impact on nursing care’.

As you are someone who is living with dementia and is living in this nursing home, I am inviting you to take part in this study. Before you decide whether or not to take part, I want you to understand why this research is being done and what it would involve. Please take time to read the following information. If you have any queries or questions before you make your decision, I would be very happy to have a discussion with you.

Research Summary

Research has shown that nurses find it particularly difficult to provide care for individuals with dementia and more so when sexual expressions are evident. Therefore, this research aims to explore this in more depth in order to help improve care for persons living with dementia who express themselves sexually. This

research study will help us to learn more about sexual expression in persons living with dementia, and how it effects nurses working in nursing homes.

If, having read this leaflet, you are interested in participating in the research, then we can arrange a meeting either in the nursing home or any other place you choose, at a time that is most convenient for you. The purpose of this meeting is to discuss the study in more depth. **The researcher will go through this information leaflet with you and answer any questions you have.**

What is the purpose of this study?

The purpose of this study is to gain knowledge on the meaning of sexual expression in persons living with dementia and how it effects nurses working in nursing home settings.

Why have I been asked to take part?

You are being invited to join this study because I want to learn about your care perspectives and experiences, and how you feel your sexuality and sexual expression is being supported by the nursing team while residing in this home. This will help us to better understand how sexual expression is currently perceived by yourself and the nursing team and what responses/interventions are currently being used to respond to sexual expression by persons living with dementia.

Do I have to take part?

No. It is up to you to decide whether or not you wish to take part in the study. If you do wish to participate, we will ask you to sign a consent form. You are still free to withdraw at any time without giving a reason. You can also choose to receive more information about the study and participate in the study at a later date.

What is the overall design/plan of the research?

I will be visiting and working in the nursing home as a staff nurse in an honorary capacity. This will allow me to work closely with the nursing team throughout the study and build up relationships with nurses and persons with dementia who are living in this nursing home. The total time I will be in the nursing home will be between 2-4 months. During this time, I hope to have unstructured/conversations interviews with approximately 10 members of the nursing team semi-

structured/conversational interviews, which aims to discover the experiences of sexual expression in persons living with dementia. I will also be asking the nursing staff if I can conduct participant observations, where I will be observing how nursing staff interact with persons living with dementia.

Following on from exploring nurses experiences of sexual expression in persons living with dementia, I will then seek to recruit persons living with dementia and inviting them to take part in conversational interviews to understand the meaning of sexual expression from their perspectives. This allows me to gain deeper insights into nursing care of persons living with dementia and to suggest and develop person-centred principles and guidance which will contribute to evidence base nursing.

What will happen to me if I take part?

I will be inviting you to have conversational interviews with myself. Conversational interviews will allow you to share your care experiences with me and how you feel the nursing team have supported your care needs. As this study is exploring 'sexual expression in people living with dementia' I will be looking to have a conversation about your sexual wellbeing and how you feel this has or hasn't been supported while living in the nursing home. These conversations will be semi-structured so you can tell the researcher as much or as little as you wish. The number of conversations and the length of time each conversation takes will be determined by you and you can stop and/or terminate the conversation at any time. You can also choose where you would like the conversation to take place. Through speaking with you, we can get some valuable knowledge on sexual expression in persons living with dementia which will contribute to the development of a person-centred way of assessing and responding to sexual expression.

What are the possible benefits of taking part?

You may not get a direct benefit from taking part in this study. However, sometimes when people are asked to participate in research that involves asking them to talk about and share their experiences, it can help them to understand their situation and experiences better.

By participating in this research, you will be helping us better understand the phenomenon of 'sexual expression' and how nurses can support and respond to

sexual expression in ways that are sensitive, support the needs of people living with dementia and provide high-quality person-centred care. You will also be contributing to publication on future nursing practice and dementia care in relation to sexual expression.

What are the possible disadvantages of taking part?

The topic of sexuality and sexual expression could be sensitive to people, thus having the potential to lead to feelings of stress or could be upsetting for people. You may discuss a situation that you have found challenging and/or upsetting. Therefore, you will always have the opportunity to take a break from the conversation, or to withdraw from the study completely. Arrangements can also be made for you to speak to the researcher about what has upset you, or to speak to a consultant independent of your care, should you wish.

If you choose to stop the conversations the researcher will ask you if you would like to finish the conversations on another occasion, but this would be your choice. Some people do find it helpful to have the opportunity to talk about their experiences even if this is hard at times. After each discussion all participants will be offered a follow-up consultation or a contact will be provided for additional support.

Will my taking part in the study be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. Access to your personal information is for the purpose of this study only and is restricted to the researcher. The information collected from you, and about you, will be stored on a secure password-protected computer and in a locked filing cabinet. All information collected will be fully anonymised and no identifying details will ever be made public. With your consent, I may use quotes from you and other participants in the results of the study. You may recognise the quotes but they will not be linked to your name or identity.

The only exception where we may need to breach confidentiality is if during the interview information is shared that highlights issues of concern around risk to yourself or others, or poor practice. As healthcare professionals I have a duty of care to raise issues of concern through appropriate channels in the organisation involved. This will be discussed with you.

Can I agree now and change my mind later?

Yes. It is possible to withdraw from the study if you change your mind later on. If you choose to withdraw we will ask you if any information that has been collected from you, and about you, can still be used in the results of the study. If you would prefer to withdraw all information collected it will be destroyed using confidential means and will not be used for research.

What will happen to the results of the study?

The results of the study will be written up for publication in journal articles and will be presented at national conferences and educational seminars. We will also report the findings to relevant expert panels and other stakeholders. You will not be identifiable in any reports or published results.

What happens when the study is finished?

At the end of this study the information collected from you and about you will be retained for five years. The permanent disposal of this data will then be arranged in line with current guidelines.

What if there is a problem?

If you have a concern about any aspect of this study please speak to the researcher or the independent advisor who will do their best to answer your questions.

Contact details of the researcher

Name of researcher: Karen Rennie

Address: PhD Candidate,
Centre for Person-centred Practice Research
Division of Nursing, School of Health Sciences
Queen Margaret University, Edinburgh
EH21 6UU

Email / Telephone: krennie@gmu.ac.uk / 0131 474 0000

Contact details of the independent adviser

Name of adviser: Dr Fiona Kelly

Address: Lecturer, Division of Nursing, School of Health Sciences
Queen Margaret University
Queen Margaret University Drive
Musselburgh
East Lothian
EH21 6UU

Email / Telephone: fkelly1@qmu.ac.uk / 0131 474 0000

Who is overseeing the research?

This study is led by Queen Margaret University.

Dementia Helpline (24 hours)

0808 808 3000

Appendix 7: Information Summary Sheet for Persons Living with Dementia



Queen Margaret University
EDINBURGH

Monday 11th November 2019
Version 1

Research Study Summary:

“Sexual Expression in Persons Living with Dementia and Impact on Nursing Care in Care Home Settings”



My name is Karen Rennie and I am a full-time PhD Candidate at Queen Margaret University within the Centre for Person-Centred Practice Research. I am a registered nurse and work in a nursing home in Edinburgh as a staff nurse.

The purpose of this study is to gain knowledge on the meaning of sexual expression in persons living with dementia and how it effects nurses working in nursing homes.

You are being invited to join this study because I want to learn about your care perspectives and experiences, and how you feel your sexuality and sexual expression is being supported by the nursing team while living in the care home. This will help us to better understand how sexual expression is currently perceived by yourself and the nursing team and what responses/interventions are currently being used to respond to sexual expression by persons living with dementia.

I will be visiting and working in the care home so I can get to know you better. I will be inviting you to have conversational interviews with myself. Conversational interviews will allow you to share your care experiences with me and how you feel the nursing team have supported your care needs.

If you have any queries or questions before you make your decision, I would be very happy to have a discussion with you.

Appendix 8: Information Sheet for the Nursing Team



Tuesday 10th September 2019
Version 1

Queen Margaret University
EDINBURGH

Information Sheet for Potential Participants: The Nursing Team **“Sexual Expression in Persons Living with Dementia and Impact on Nursing** **Care in Nursing Home Settings”**

As a member of the nursing team in this nursing home, I am inviting you to take part in my study. My name is Karen Rennie, and I am a full-time PhD Candidate at Queen Margaret University within the Centre for Person-Centred Practice Research. I am a registered nurse and work in a nursing home in Edinburgh as a staff nurse. My PhD topic is exploring sexual expression in persons living with dementia and how that impacts on nursing care.

Before you decide whether or not to take part, I want you to understand why this research is being done and what it would involve. Please take time to read the following information. If you have any queries or questions before you make your decision, I would be very happy to have a discussion with you.

What am I trying to find out (research)?

Research has shown that find it particularly difficult to provide care for individuals with dementia and more so when inappropriate sexual expressions are evident. Therefore, this research aims to explore this in more depth in order to help improve care for persons living with dementia who express themselves sexually. This research study will help us to learn more about sexual expression in persons living with dementia, and how it effects nurses working in nursing homes.

If, having read this leaflet, you are interested in participating in the research, then we can arrange a meeting either in the nursing home or any other place you choose, at a time that is most convenient for you. The purpose of this meeting is to discuss the

study in more depth. **The researcher will go through this information leaflet with you and answer any questions you have.**

What is the purpose of this study?

The purpose of this study is to gain knowledge on the meaning of sexual expression in persons living with dementia and how it effects nurses working in nursing homes.

Why have I been asked to take part?

You are being invited to join this study because I want to learn about your perspectives and experiences relating to caring for people living with dementia, especially caring for those who express themselves sexually. This will help us to better understand how the nurses working in nursing homes currently perceive sexual expression and what responses/interventions nurses are currently using to respond to sexual expression in persons living with dementia.

Do I have to take part?

No. It is up to you to decide whether or not you wish to take part in the study. If you do wish to participate, we will ask you to sign a consent form. You are still free to withdraw at any time without giving a reason. You can also choose to receive more information about the study and participate in the study at a later date.

What is the overall design/plan of this research?

I will be visiting and working in the home as a registered nurse in an honorary capacity. This will allow me to work closely with the nursing team throughout the study and build up relationships with nurses and persons with dementia who are living in the nursing home. The total time I will be in the home will be between 2-4 months. During this time, I hope to have unstructured/conversational interviews with approximately 10 members of the nursing team semi-structured structured/conversational interviews, which aims to discover the experiences of sexual expression in persons living with dementia in nursing home settings. I will also be asking the nursing staff if I can conduct participant observations, where I will be observing how nursing staff interact with persons living with dementia in the home.

Following on from exploring nurses experiences of sexual expression in persons living with dementia, I will then seek to recruit persons living with dementia and inviting them to take part in conversational interviews to understand the meaning of sexual expression from their perspectives. This allow me to gain deeper insights into nursing care of persons living with dementia and to suggest and develop person-centred principles and guidance which will contribute to evidence base nursing.

What will happen to me if I take part?

I will be inviting you to have informal conversations with the researcher. Informal conversations will allow you to share your experiences of providing care for persons living with dementia, especially when you have cared for someone living with dementia who has expressed themselves sexually. These conversations will be unstructured so you can tell the researcher as much or as little as you wish. You will determine the length of time the conversational interviews will take, and you can stop and/or terminate the conversation at any time. You can also choose where you would like the conversation to take place and if you would like to have more than one interview.

In addition to interviews, I will be inviting you to agree to participate in observations of practice. I will observe care giving between nurses and people living with dementia and observe how nurses respond to persons with dementia who express themselves sexually and how they interact with each other. This will allow the researcher to witness any positive care experiences and outcomes between nurses and persons living with dementia. Observing practice will also allow me to try to understand any expressions that have resulted in a negative experience. I will be taking a non-judgmental stance as observations are purely about gaining understanding. Observations will take place in communal areas in the home, such as corridors, lounges, dining rooms, unless privacy is needed. No observation will be taking place during any form of personal care giving or private moments. In addition, no observation will be taking place behind curtains or whenever someone needs privacy. Data extracted will only be of observations of the nursing staff who agree to be observed.

Through both observations of practice, and from speaking with you, we can get some valuable knowledge on sexual expression and persons living with dementia,

which will contribute, to the development of a person-centred way of assessing and responding to sexual expression.

What are the possible benefits of taking part?

You may not get a direct benefit from taking part in this study. However, sometimes when people are asked to participate in research that involves asking them to talk about and share their experiences, it can help them to understand their situation and experiences better.

By participating in this research, you will be helping us better understand the phenomenon of 'sexual expression' and how nurses can support and respond to sexual expression in ways that are sensitive, support the needs of people living with dementia and provide high-quality person-centred care. This study will enable publication on future nursing practice and dementia care in relation to sexual expression, which will influence future nursing practice, research and policies.

What are the possible disadvantages of taking part?

The topic of sexual expression and care experiences could be sensitive to people, thus having the potential to lead to feelings of stress or could be upsetting for people. You may discuss a situation that you have found challenging and/or upsetting. Therefore, you will always have the opportunity to take a break from the research, to stop a conversation or an observation, or to withdraw from the study completely. Arrangements can also be made for you to speak to the researcher about what has upset you, or to speak to a consultant independent of your care, should you wish.

If you choose to stop the observations or conversations, the researcher will ask you if you would like to participate in observations or finish the conversations on another occasion, but this would be your choice. Some people do find it helpful to have the opportunity to talk about their experiences even if this is hard at times. After each discussion or a set of period of observation, all participants will be offered a follow-up consultation or a contact will be provided for additional support.

Will my taking part in the study be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

Access to your personal information is for the purpose of this study only and is restricted to the researcher. The information collected from you, and about you, will be stored on a secure password-protected computer and in a locked filing cabinet. All information collected will be fully anonymised and no identifying details will ever be made public. With your consent, I may use quotes from you and other participants in the results of the study. You may recognise the quotes but they will not be linked to your name or identity.

The only exception where we may need to breach confidentiality is if during the interview information is shared that highlights issues of concern around risk to yourself or others, or poor practice. As healthcare professionals I have a duty of care to raise issues of concern through appropriate channels in the organisation involved. This will be discussed with you.

Can I agree now and change my mind later?

Yes. It is possible to withdraw from the study if you change your mind later on. If you choose to withdraw we will ask you if any information that has been collected from you, and about you, can still be used in the results of the study. If you would prefer to withdraw all information collected it will be destroyed using confidential means and will not be used for research.

What will happen to the results of the study?

The results of the study will be written up for publication in journal articles and will be presented at national conferences and educational seminars. We will also report the findings to relevant expert panels and other stakeholders. You will not be identifiable in any reports or published results.

What happens when the study is finished?

At the end of this study, the information collected from you will be retained for five years. The permanent disposal of this data will then be arranged in line with current guidelines.

What if there is a problem?

If you have a concern about any aspect of this study please speak to the researcher or the independent advisor who will do their best to answer your questions.

Contact details of the researcher

Name of researcher: Karen Rennie

Address: PhD Candidate,
Centre for Person-centred Practice Research
Division of Nursing, School of Health Sciences
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EH21 6UU

Email / Telephone: krennie@qmu.ac.uk / 0131 474 0000

Contact details of the independent adviser

Name of adviser: Dr Fiona Kelly

Address: Lecturer, Division of Nursing, School of Health Sciences
Queen Margaret University
Queen Margaret University Drive
Musselburgh
East Lothian
EH21 6UU

Email / Telephone: fkelly1@qmu.ac.uk / 0131 474 0000

Who is overseeing the research?

This study is led by Queen Margaret University with oversight from NHS Lothian. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee (REC).

Appendix 9: Consent Form for the Nursing Team

Tuesday 10th September 2019
Version 1



Queen Margaret University
EDINBURGH

Consent Form: Nursing Team

“Sexual Expression in Persons Living with Dementia and Impact on Nursing Care in Nursing Home Settings”

Please tick/initial boxes

I have read and understood the **Information Sheet for Potential Participants: The Nursing Team, version 1, 10.09.19** and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree to participate in this study.

Name of participant: _____

Signature of participant: _____

Signature of researcher: _____

Date: _____

Appendix 10: Personalised Research Plan for Persons Living with Dementia Participating in the Research

Personalised Research Plan for Persons Living with Dementia Participating in the Research

Persons Name:

What the person prefers to be called:

What is the life history of the person? (e.g. what is meaningful for the person on a day-to-day basis? What significant events has the person had in their life? What activities does, or did, the person enjoy doing? What parts of life does the person find unenjoyable?)

What relationships are important to the person? (e.g. who matters to the person living with dementia? What are their perspectives of the person taking part of the research and talking about sexual expression?)

How does the person feel about taking part in the research? (e.g. Do they feel that there are advantages of taking part in the research? Does the person feel that there could be any disadvantages of taking part in the research? What are they looking forward to most/least about taking part in the research? Does the person and legal representative/healthcare professional have any worries about the person taking part in the research?)

How does the person cope with feeling distressed/upset? (e.g. How does the person usually express feelings of distress? Ho they and/or others usually respond too and manage having sensitive conversations or how to respond to the person if they get upset? What provides the person for comfort?)

Does the person have any questions about the research?

Is the person happy/satisfied with the research plan for talking about sexual expression?

Appendix 11: Participant Observation Guide (Adapted from Merriam 1988 and Dewing et al. 2014).

Participant Observation Guide (adapted from Merriam 1988 and Dewing et al. 2014).

Describe the physical environment (what do I see, hear, feel and/or imagine):

Describe the participants (what do I see, hear, feel and/or imagine):

Describe interactions and activities (what do I see, hear, feel and/or imagine):

What is my role/position/behaviour/influence during this observation:

Appendix 12: Reflecting on Field Notes Template

Reflecting on Field Notes

Date:

Time:

Venue:

Research Activity:

Description of the experience:

Reflection on Relationality:

Reflection on Corporeality:

Reflection on Spatiality:

Reflection on Temporality:

My feelings about this experience:

How was sensuousness present in this experience?

What is meaningful/significant about this experience?