

Becoming Intersubjective *in medias res* of Behaviours  
that Challenge in Dementia: A Layered  
Autoethnography.

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I declare that this thesis is my own work and has not been submitted for  
the award of a higher degree elsewhere

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**Title: Becoming Intersubjective *in medias res* of Behaviours that Challenge in Dementia: A Layered Autoethnography.**

**Abstract**

Behaviours that challenge in dementia, often described and diagnosed as behavioural psychological symptoms in dementia (BPSD) are experienced by over 90% of people living with dementia, and 75% of those admitted to hospital, with 43% of nurses reporting these behaviours as severely distressing to them.

During behaviours that challenge moments in dementia there is an intersubjective relationship between the person living with dementia and the nurse. This can lead to both the nurse and the person living with dementia experiencing a variety of emotions. I suggest that much of the emotion that exists is created by interactions between our lived stories, which also have the potential of influencing the intersubjective experiential outcome.

The study aims to make sense of my (first-person) experiences of intersubjectivity *in medias res* (Latin for in the midst) of behaviours that challenge in dementia, and also consider how I as a nurse can manage that intersubjective moment to achieve a positive outcome.

I used layered autoethnography as my study's methodology to gather retrospective personal and professional experiential data in moments where 'I' as a nurse have faced personal and professional challenges, and in doing so made relational connections between the two. To explore these connections my study was framed within a Deleuzian theory of time, where the pure past, meets the living present, creating a transient becoming future synthesis. Data was managed and analysed through rhizoanalytical methods, including *Deleuzian-Guattarian* rhizomatic mapping.

The study established that although the ability to remain intersubjective remains for people living with dementia, interactions are often on an emotional level and not always based in the living present. It is therefore my role as a nurse to consider the story of other, whilst also evaluating self during moments of challenge by engaging in metacognitive and empathically curious nursing practice.

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# **1 Chapter 1 - Background to Subject**

## **1.1 Introduction to chapter**

My first chapter introduces the subject and topic of my thesis. These are behaviours that challenge in dementia and intersubjectivity. These behaviours and intersubjective relationships are discussed in the context of a large general hospital environment where I worked as a mental health liaison nurse. The chapter initially discusses what is meant by the term behaviour, and how behaviours that challenge present in people living with dementia. The chapter later considers how behaviours that challenge in dementia can develop and maintain, but also how they impact on the person living with dementia and the nurses providing the care (in the case of my study this will be me). The impacts of behaviours that challenge discussed include, care provision, financial implications, and treatment/management decision making. However, most importantly perhaps, the chapter discusses the impact of behaviours that challenge on the personhood (Kitwood, 1997) of both the person living with dementia and the nurse providing the care.

## **1.2 What do I mean by behaviours that challenge?**

The word 'behaviour' was purportedly introduced to society in the 15<sup>th</sup> century when it was associated with the use of manners. However, by the 16<sup>th</sup> century the meaning implied the potential of causing effects on others. A pathological meaning of the word behaviour was not actually introduced until the mid to late 19<sup>th</sup> century (Chaney, 2010). This medicalisation of the word behaviour arose partly from the recognition that changes in behaviours could be a component of a disturbance of the mind and may not be a purely criminal act as previously perceived (Bewley, 2008). Alongside this recognition there was also a growing need at this time for institutional asylum providers

to justify that behaviours presented were pathological in nature due to growing public opposition to the use of chemical and physical restraint (Hide, 2014).

For the purpose of my study, when I refer to behaviours that challenge in dementia, I am referring to any behaviour where specialist mental health intervention or treatment was requested, or provided, by the mental health liaison service in which I worked in a general hospital. When referring to my personal experiences of behaviours that challenge, I am referring to any behaviours in which I, or others I know or have met, have presented with behaviours which have impacted on other (including me) emotionally, psychologically, or physically.

### **1.3 What are behaviours that challenge in dementia?**

Dementia is an overarching term that describes a wide range of symptoms of cognitive loss due to pathological neural and/or cerebral damage, or deterioration that effects a person's memory, thinking skills, emotions, and behaviours (Alzheimer's Association, 2017). These changes include judgement, understanding, and recall, as well as other functions such as movement and speech; all of which are severe enough to reduce a person's ability to perform activities of daily living (Alzheimer's Association, 2017; NHS Choices, 2017). This loss of functioning can lead to behaviours that are often described and diagnosed as Behavioural Psychological Symptoms of Dementia (BPSD). These behaviours include; aggression – hitting, biting, scratching, or throwing things, non-concordance with care – personal care, eating and drinking, walking or pacing or agitation – wandering or absconding, disinhibition – disrobing, sexualised behaviour or verbal insults (Draper & Wand, 2015).

I prefer to use the term behaviours that challenge in dementia rather than BPSD, as it places the emphasis of the challenge on the recipient of the behaviour. I make this point as I note that what others might find challenging, I may not. However, prior becoming a nurse I worked as a support worker with a variety of people who had presented with behaviours that were deemed societally and/or criminally challenging. Incidents I faced during this support role included being threatened by a client holding a kitchen knife who had stabbed his previous support worker, and also being held hostage in a room by a client wielding a hammer. Nevertheless, as a care provider we did not use restraint or place blame, we instead showed love, compassion, and care, and gave a safe place for clients to explore their behaviour and who they were.

Therefore, for the purpose of thesis I need to be open and honest that my point of reference and threshold for what 'I' consider challenging is high. I am also mindful that behaviours that challenge are not always physical and can also present as verbal and emotional challenge. Behaviours that challenge in dementia can also come from the most unexpected sources (Hallett, 2018) appearing impulsive, disproportionate, and at times out of context to the believed trigger situation (Cerami & Cappa, 2013; Ibañez & Manes, 2012). These unpredictable behaviours in dementia are thought by some to be due to impaired social cognitive processes (e.g., facial recognition, emotional interpretation, decision making, understanding of social norms / attitudes and empathy) (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2016).

Understanding behaviours that challenge in dementia can be problematic if they are seen simply as a pathological concept as they become categorised as a mere phenomenon (Murphy, 2015). This clinical categorisation only affords the observer

with a suggestion of causation, it however offers little in terms of guidance on how to support the person with dementia (Dupuis, Wiersma, & Loiselle, 2012; Tible, Riese, Savaskan, & Von Gunten, 2017). When these forms of behaviours are purely pathologised they are in effect assigned a moral code (Dupuis et al., 2012). This is a code that can only be unlocked by a subjective moral measurement of the person's intent or cognitive functionality by the recipient of the behaviour (Dupuis et al., 2012). It therefore offers little explanation or understanding of whether the individuals' behaviours are somehow shaped or biased by their personal, historical, biographical schemas, or understandings of the world (Dupuis et al., 2012; Schwartenbeck et al., 2016). This risks the formation of a perspective that people presenting with these behaviors are not conforming to the fixed rules of the environment, and therefore must be labeled as somehow deviant (Schwartenbeck et al., 2016). This is somewhat contradictory to the arguments that behaviours that challenge in dementia are triggered by environmental, psychosocial, and biological factors, and are not a chosen act of defiance (Corbett, Burns, & Ballard, 2012).

Environmental factors such as lighting, noise and a lack of stimulating activity can lead to behaviours that challenge in dementia (Scales, Zimmerman, & Miller, 2018). Environment is a particularly important factor when considering a person living with dementia's behaviour (Tible et al., 2017) as each person will draw on their unique beliefs and experiences in response to the setting they find themselves in (Wicker, 2011). The setting itself can interrupt a person's psychosocial coping mechanisms or provoke the presence of personality traits attributed to negative past experiences (Rouch et al., 2014). Personality trait led behaviour is nevertheless not just a factor for the person living with dementia, but also the nurse, with some nurses being more interactive

and relational than others (Clissett, Porock, Harwood, & Gladman, 2013). It has been noted that nurses often conform to a nursing stereotype within a clinical environment, rather than act within their own values and moral beliefs; leading to burnout in some cases (Goethals, Gastmans, & De Casterlé, 2010; Johnson, 2015). This is particularly the case when nurses feel challenged by others, especially when they sense they have been organisationally unsupported (Toon, 2014; Liu, et al., 2018). This leaves the nurse facing a clash between their personal values and the professional expectations of their role when faced with behaviours that challenge (Stacey, Joynson, Diamond & Stickley, 2011).

It has been acknowledged that the choices and decisions made by nurses around what treatment or support to offer is difficult for nurses when they are presented with behaviours that challenge in dementia (Melander, Sävenstedt, Olsson, & Wälivaara, 2017; Yous, Ploeg, Kaasalainen & Martin, 2019). Some of the causes cited for this lack of decision making are; a lack of confidence, time restrictions, and the introduction of task orientated care, all of which can lead to frustration and a communication breakdown between the nurse and person living with dementia (Moonga & Likupe, 2016; White et al., 2016). Therefore, the impact of the relationship between the nurse and the person living with dementia should not be ignored as a potential instigating, mediating, or maintaining factor of the behaviour that presents (Bramley & Matiti, 2014).

In conclusion, “The etiopathogenesis of behaviours that challenge is often complex, with multiple contributing direct factors and indirect mediators” (Tible et al., 2017. p.298). These factors include a range of biopsychosocial influences and narratives.

However, these factors are not exclusive to the person living with dementia but can also influence the nurses' behaviour and decision making. I too as a nurse acknowledge that I will have biopsychosocial factors which may influence my behaviours and responses to others. However, as yet I have not explored what they might be, and how they play out in my intersubjective relations and decision making when supporting people living with dementia, especially at times of challenge.

#### **1.4 How are people presenting with these behaviours being supported?**

Treatments for behaviours that challenge in dementia have been researched widely over the last decade leading to extensive guidelines and recommendations (NICE -SCIE, 2006; Royal College of Psychiatrist, 2005). Often the first line treatments for people living with dementia who present with these behaviours are pharmaceutical (Tible et al., 2017; Walsh, 2016), including an over use of antipsychotics (Gill, Almutairi, & Donyai, 2017). This however conflicts with treatment guideline recommendations which promote their use only in cases of severe agitation, or an immediate risk to self or others (Banerjee, 2009; Gill et al., 2017; NICE -SCIE, 2006).

In a general hospital environment it is recommended that psychotropic medication treatment decisions are guided and supported by mental health liaison services. However, these services are varied nationally (Naidu, Bolton, & Smith, 2015; NHS England et al., 2016) with many mental health liaison services only focusing on emergency departments leading to a lack of in-patient mental health specialist provision (Mukaetova-Ladinska, 2016). Currently, there is little national continuity across mental health liaison services (RCN, 2011; Walker, et al., 2018). This has arguably led to a lack of consistency in treatment decision making across healthcare providers, and

variations in their local behaviours that challenge in dementia treatment guidance (RCN, 2011; Walker, et al., 2018).

There are of course alternative support options for people living with dementia who present with behaviours that challenge, and these include several non-pharmacological interventions (Abraha et al., 2017). However, these interventions are somewhat reliant on nurses intervening with tailored and individualised care to meet the person's needs (Kales, Gitlin, & Lyketsos, 2015) which requires planning, time, and a desire to provide (Ijaopo, 2017). This is in a culture where many nurses are reporting their role as the provision of medical (pharmacological) treatments or interventions; citing a lack of time, resources, and staff to provide non-pharmacological or person centred care (Ervin, Cross, & Koschel, 2014; Ross, Tod, & Clarke, 2014).

Nevertheless, if mutual respect is delivered as an integral component of all care, even in times of resource austerity (Kerasidou, 2019), there is no reason why person-centered care moments should not exist (Kitwood, 1997; McCormack, Dewing, & McCance, 2011). One way of acknowledge these moments is to always recognise the person living with dementia's "Personhood" (Kitwood, 1997, p.8). Kitwood (1997, p.8) describes Personhood as "a position or social relationship that is bestowed on one human being by others, in the context of relationship and social being".

### **1.5 What about exploring the person behind the behaviour?**

The late Tom Kitwood was for many academics and dementia clinicians the pioneer in the drive for the person-centred care of people living with dementia and their carers (Kitwood, 1997; NICE -SCIE, 2006). He was reported to be heavily influenced by

Buber's "I-It" and "I-Thou" relational model, and in doing so moved away from an "I"- "It" narrative in dementia care (Buber, 1970 p. I). This relational model (Buber, 1970) discourages the alienation or the objectification of all people, which in the case of my study includes people living with dementia. Buber (1970) argues that we are unable to offer authentic relationships if we separate ourselves from others by only viewing them as objects of difference, or somehow inferior (DeVault, 2013). He states that, "egos appear by setting themselves apart from other egos.... persons appear by entering into relation with other persons" (Buber, 1970, pp. 111-112).

This sentiment emphasises the challenge and conflict nurses have in balancing the expectations of their role as care providers whilst also addressing their sense of self when faced with behaviours that challenge. Kitwood (1997 p.15) talks about this conflict as the balance between the "experiential" and "adapted self", with the latter referring to socially acceptable roles which are often associated with a person's employment, or social status (Nurse). This form of personhood is best explained by the term moral personhood (Hughes, 2014). Moral personhood seeks to explore our responses and interaction with others, which of course can be influenced and measured by the rules of the culture and the social status in which we operate (Brennan, 2018; Himma, 2005).

Myser (2007, p58) emphasises that a person living with dementia can be perceived as having a "fading personhood", and therefore are often reliant on others to construct or maintain their personal identity. It has been argued that an ageing brain leads to the loss of the moral status and the autonomy of personhood as a consequence to the fading of subjective agency (Higgs & Gilleard, 2016). This is unlike the nurse providing the care,

as they continue to have the capacity for an autonomous personhood and agency, predominately constructed through self-exploration and/or feedback from others (Bernstein, 2015). Therefore, all efforts should be made to support and maintain the full personhood of people living with dementia (Higgs & Gilleard, 2016). Without this, I as a nurse may be directed by my subjective value judgements alone, and the person living with dementia could be seen as a “non-person” (Alzheimer Europe, 2013; Higgs & Gilleard, 2016 p.774; Ohlin, 2005).

### **1.6 Impacts of behaviours that challenge in dementia on care provision**

As previously discussed, there has been extensive research into the treatment and support of behaviours that challenge in dementia (often referred to as ‘management of’) leading to a growing recognition of the need to understand these behaviours in nursing practice (Braun et al., 2018; Murphy & Maidens, 2016). Research indicates that behaviours that challenge are experienced by >90% of people living with dementia (Fernandez-Martinez et al., 2010). In the context of my study, which is based in a general hospital environment, 75% of people living with dementia admitted to hospital are reported to display behaviours that challenge moments during their stay (Alzheimer’s Society, 2009). In addition, 56% of this cohort will present with one episode of aggression towards others (Gallagher et al., 2016; White et al., 2016). This is not just a challenge faced by hospital nursing staff as 76% of people living with dementia residing in care homes will also present with behaviours that challenge (Buhr & White, 2007), of which 43% of incidents are reported as moderately to severely troubling to nursing staff (Sampson et al., 2014).

A recent longitudinal study into behaviours that challenge in dementia found that hallucinations and aggressive disturbances were presentations that caused nursing staff the most concern (White et al., 2016). When people living with dementia presented with these phenomena 55% of them received medication (typically antipsychotics), with 22% receiving restraint (93% used bedrails) and only 17% received nursing one to one intervention (White et al., 2016). And yet, evidence indicates that only 10% of people living with dementia presenting with these behaviours actually get the correct pharmaceutical treatment (Van der Spek et al., 2016).

On reading the literature around treatment and support I was very mindful that all these decisions took place in environments where nurses reported a limited understanding of how to support people living with dementia experiencing these behaviours (Harwood, 2017). This not only leads to frustration and distress for the person living with dementia, but also their care providers, which includes nursing staff (Gallagher et al., 2016). The frustration felt by nurses, and the lack of de-escalation and non-pharmacological interventions was often reported to be due to a lack of confidence in treatment decision-making (Yous et al., 2019). This has arguably steered treatment towards a medicalised response characterised by a narrative of control and management, rather than exploring how we can support and understand why people living with dementia are (personally) presenting with these behaviours (Harwood, 2017).

It is acknowledged that non-pharmacological behavioural interventions cost nearly £27.6 million more than using antipsychotic drugs dementia (Sorroza Lopez & Martino-Roaro, 2016). However, for every pound invested in non-pharmacological behavioural interventions it would result in nearly two pounds in health savings and quality of life

outcomes (NHS Institute for Innovation and Improvement, 2011). When measuring quality of life outcomes alone, the use of non-pharmacological behavioural interventions rather than antipsychotics for the treatment of behaviours that challenge would lead to an estimated saving of £54.9 million per year in England alone (NHS Institute for Innovation and Improvement, 2011). Non-pharmacological interventions, led by nurses, do not only have a potential financial cost saving, but perhaps more importantly have a significant impact on the person living with dementia's quality of life and wellbeing (Banerjee, 2009; NHS Institute for Innovation and Improvement, 2011; Brechin, Murphy, James & Codner, 2013).

### **1.7 Rationale for Meta-Ethnography**

As discussed in my subject/topic section there is significant amount of evidence that moments of behaviours that challenge in dementia can be distressing for both the person living with dementia and the nurses caring for them. These moments are present in large numbers of people living with dementia, and the impact on their quality of life is substantial. It is a subject that has become a controversial aspect of dementia care, particularly as for the most part these moments are 'managed' by using psychotropic medication. These treatment decisions place the person living with dementia at risk of cerebral vascular decline, a deterioration in their cognition, and at times, even death (Tampi, Tampi, Balachandran, & Srinivasan, 2017). As well as the risks associated with psychotropic treatments for people living with dementia, there is also a risk that this treatment intervention becomes the default position when a nurse is presented with behaviours that challenge. This default position offers very little in terms of understanding the biopsychosocial factors behind the presenting behaviour in order to support future (interventions / treatment) decision making.

When I reflected on this, I wondered why pharmacological options were so prevalent across general hospital environments when addressing behaviours that challenge in dementia, and why behaviours that challenge was so troubling to nurses working in these environments. I concluded that there were likely a multitude of reasons and factors behind these nursing decisions and negative intersubjective experiences, and it was improbable I could address all of these factors in my thesis. I could however look at my own practice and subjective experiences and hope that my study findings would resonate with other nurses. However, to do this I decided I would need to initially explore if people living with dementia could still be intersubjective, and if so, what factors of intersubjectivity are present and how can they be nurtured.

To answer these questions, I decided to use meta-ethnography as my method of literature exploration and synthesis. My literature synthesis was designed to not only seek to answer the question of what is intersubjectivity for a person living with dementia, but also to act as a guide for my overall thesis and study direction. If I am to seek to understand my own subjective experiences as a nurse in an intersubjective event (behaviours that challenge in dementia) then it only makes sense that I first explore what the subjective experience of a person living with dementia may be within those intersubjective moments. How I did this would be guided by my meta-ethnography findings.

Therefore, to do this, my meta-ethnography aims were to:

1. Explore if the ability to be intersubjective remains present in people living with dementia?
2. And, if the ability to be intersubjective remains present for people living with dementia how does it present, and how can it be nurtured?

## **2 Chapter 2 - Literature Review**

### **2.1 Introduction to chapter**

Initially I was unsure how to use my literature review, where it would sit within my study, or whether indeed to do one; which is not unusual when using autoethnography as a study methodology (Gariglio, 2018). Wall (2008) refers to the need for autoethnographers to talk to the literature, rather than using literature reviews as a way of finding gaps or weaknesses in the studies of others. In a conventional thesis there is a strong drive to critique other literature for their methodological or theoretical robustness (Johnston & Strong, 2008). I did not want this to be the role of my literature review. I wanted it instead to guide the direction of my thesis by informing my narrative on the subject, and develop my story (Forrester, 2012; Johnston & Strong, 2008). However, as I began to collect and read raw data I realised that a literature synthesis could also develop, or unearth, a conceptual or theoretical construct which may support and frame my study. Therefore, with these points in mind I decided to place my literature review before the introduction of my study, but after the introduction of my topic and rationale. This allowed my literature review to be the prologue to my story (study); a story that is yet to be (Johnston & Strong, 2008).

### **2.2 Introducing Intersubjectivity to my meta-ethnography**

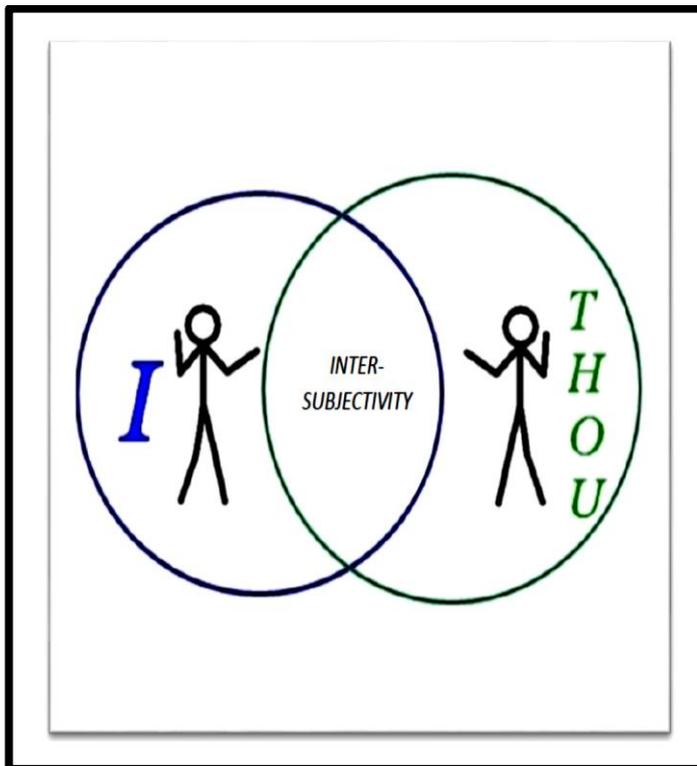
Intersubjectivity is a philosophical concept (mind/body/soul/matter) which recognises the influences of other on the mind and consciousness. This was first discussed in this context by Descartes in the 17th Century (Fullbrook, 2004; Rochat, Passos-Ferreira, & Salem, 2009). Intersubjectivity is described as a shared emotional, linguistic, perceptual or cognitive meaning or understanding of any given situation via a transfer of energy between two or more subjects (Decety & Lamm, 2009; Zlatev, Racine, Sinha, &

Itkonen, 2008). It is however a controversial subject which can create debate due to it being grounded in two polarised paradigms; firstly, traditional objective (positivist) science, and secondly humanistic subjective (constructivist) social science (Di Paolo & De Jaegher, 2015; Pierson, 1999).

This paradigmatic argument is not one that only takes place in research, but also takes place in nursing practice. It has been argued by some that this power struggle between these opposing paradigms has moved nursing care from being subjective focused care, towards an objective, mechanistic, diagnostic, problem focused, and de-humanised care provision (Pierson, 1999; Jeffrey, 2016; Warelow, 2013). However, Fabian (2014) believes that social sciences, mainly in the form of phenomenology, have now taken away the control and ownership of intersubjectivity from the quantitative paradigm, and placed it back within an experiential and qualitative narrative.

This paradigmatic shift has created a nursing narrative where the mere mention of positivism in nursing research is considered “anachronistic” (Corry, Porter & McKenna, 2018 p.10). This shift in paradigm has led to a new focus in nursing towards consultation and collaboration through human interaction and empathy (Bickerton, Procter, Johnson & Medina, 2011). Although one must be mindful that even though this humanised approach to dementia care is admirable, it can also become a “fallacy of care” (Leibing, 2019 p.6) if the love and compassion provided hides poor practice or treatment gaps. During intersubjective moments there is a balance to be struck between meeting a task orientated need of the person living with dementia, and their need for human connection; a place where patient need meets human need (Hansen, Hauge, & Bergland, 2017).

Edmund Husserl, a philosopher, first introduced a phenomenological transcendental form of subjectivity in the late 1920s where he described intersubjectivity as an objective “lived body” consciously experiencing “another lived body” (“the alter ego = other I”) (Husserl, 1982; Smith, 2011 p.92 & 97). This was later challenged by Alfred Schutz, a socio-phenomenologist in the mid to late 1960s (Bickerton et al., 2011; Husserl, 1982; Schutz, 1964;1967) who moved Husserl’s theory of intersubjectivity from being a focus on the ‘I’ to a position of the ‘us’, stating, “world-experience is not private experience it is shared experience” (Schutz, 1966 p.54; Trujillo, 2018). I have taken this shared description of intersubjectivity as a basis of my meta-ethnography synthesis and study. This intersubjective position is displayed in Figure 1 below (Pennsylvania Echoes, 2011).



*Figure 1* Intersubjectivity across the I &Thou

### 2.3 Background

Whether intersubjectivity is possible for people living with dementia has been much debated. Nevertheless, studies on the subject are minimal, and often only seek to explore one side of the intersubjectivity? For the most part quantitative articles I reviewed reported a reduced ability for people living with dementia to be intersubjective (Barsuglia et al., 2014; Cotelli et al., 2018; Moreau, Viallet, & Champagne-Lavau, 2013; Van der Hulst, Bak, & Abrahams, 2014). These findings tended to relate to biomedical changes and the measurement of organic cognitive consciousness, ruling out alternatives such as subjective social practices, and personal affect (Taylor, 2008). This risks the production of an argument that, “without a phenomenal and functional consciousness people are essentially higher-level automatons undergoing actions devoid of any subjectivity or conscious control” (Bandura, 2001 p3).

Although, there are strong empirical arguments, including the Theory of Mind (Premack, & Woodruff, 1978) that intersubjectivity is an innate cognitive and neuro mechanical process. This is perhaps shortsighted as it excludes the potential influence of experiential, emotional, and empathic human connections (Zlatev et al., 2008). The debate of ‘what is intersubjectivity’ has even been extended further to a tri-theory, which consists of interrelations via processes that are sub-personal (mirror neurons), functional autonomic cognitive mechanisms, and phenomenological social empathic expression (Gallese, 2001). This suggests that the process of intersubjectivity in dementia is likely to be complex and multi factorial, requiring more than just a cognitive process.

## 2.4 Method

In order to explore the presence of, and the factors associated with intersubjectivity for people living with dementia in dementia, I decided to complete a meta-ethnography seven stage synthesis (Noblit and Hare, 1988) as my literature review method/ology. Below, in Table 1 is an explanation of Noblit and Hare's (1988) seven stages of the model which will be used as sub-headings in my literature review, alongside conventional style headings.

Table 1 *Noblit and Hare's (1988) seven stages of a meta-ethnography*

<b>Seven Stages</b>	<b>Synthesis Stage</b>	<b>Example in my study</b>
Getting started	The need for an appropriate literature synthesis for my PhD – 'Making sense' – terminology & search terms	Table 2 & Table 3
Deciding what is relevant to the initial interest	Inclusion and Exclusion Criteria & PRISMA – 'Focusing the topic'.	Figure 2 & Table 4
Reading the studies	Reading / rereading – 'Finding characteristics', quality & data extraction.	Tables 5 & 6
Determining how the studies are related	Highlighting areas of studies (Highlighting Pen in MS Word) and '1 <sup>st</sup> order construct development'.	Appendix 1 (example) & Table 7
Translating the studies into one another	Continuation and repetition of above – '2 <sup>nd</sup> order construct development'.	Table 7
Synthesising translations	My interpretation and translation – '3 <sup>rd</sup> order construct development'.	Table 7
Expressing the synthesis	'Line-of-argument synthesis development'.	Figure 3

My literature review used a synthesis of qualitative literature to consider and analyse intersubjectivity by describing and reflecting on; any inter-relational and interpersonal dialogical, perceptual, or emotional connection between people living with dementia and others who provide care, either formally or informally. In doing so my literature synthesis could be used to support and guide my PhD study aims and objectives. The method of literature review chosen (meta-ethnography) provides and respects a

qualitative, interpretive, and inductive process, and therefore is appropriate to explore the presence of intersubjectivity for people living with dementia through a synthesis of qualitative studies.

Meta-ethnography can include the ability to create a testable qualitative hypothesis in the form of third order constructs, a line-of-argument synthesis, or a conceptual model (Britten et al., 2002). This is achieved by first capturing the words used by the participants in the selected studies; these are first order constructs. However, these first order constructs are only for information and synthesis initiation purposes and are not data interpretation; unlike the subsequent second order constructs (Carey, Kent, & Latour, 2019). Second order constructs are created by the assembling of the researcher/s data interpretation. These are reported as findings by the author/s of the selected studies (Smith & Anderson, 2018). These are then interpreted into third order constructs, and then developed into a thematic synthesis; or the building of a story (Lachal, Revah-Levy, Orri, & Moro, 2017). Finally, a line-of-argument moves the data from the descriptive to the conceptual (Atkins et al., 2008). Although this process is to be completed in its entirety, it is for the purpose of social or phenomenon explanation only (Brannelly, 2011) and not to develop a hypothesis to test within my study.

## **2.5 Stage 1. Getting started**

At this getting started stage of my synthesis I considered appropriate search terms to use to find suitable and relevant articles. This began with the development of keywords. To aid this I used the SPIDER search framework (Cooke, Smith & Booth, 2012) as shown below in Table 2. SPIDER was useful in that it is predominately used for qualitative study searches and is considered more effective and sensitive for guiding

qualitative literature reviews than alternative tools such as PICO (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014).

Table 2 *SPIDER search framework*

<b>S</b>	Sample	People living with dementia / care providers
<b>PI</b>	Phenomenon of Interest	Presence of and factors associated with intersubjectivity in dementia
<b>D</b>	Design	Exploratory, Experiential, Phenomenology, Social and Interpretative.
<b>E</b>	Evaluation	Narratives of intersubjective / inter-relational / interpersonal experiences of people living with dementia, and those who cared for, or supported them.
<b>R</b>	Research Type	Original Primary Qualitative Research

### 2.5.1 Key Words

Key words selected for the primary and secondary electronic search were: Dementia, Alzheimer's, Memory, Cognition, Intersubjectivity, Interpersonal and Relational (Including combinations and/or/not using Boolean Operator and phrases (Boole, 1854 in Grattan-Guinness, 2005), and wildcard and truncation symbols (\*) shown in Table 3).

Table 3 *Keywords / Search Terms*

Keywords / Search Terms	
1.	Dementia
2.	Alzheimer's
3.	Memory
4.	Cog*/nit/ive or tion
5.	Inter/Subject/ivity
6.	Interpersonal
7.	Relation*/al
8.	OR 1, 2, 3 & 4
9.	+ AND 5, 6 & 7

### **2.5.2 Identification of studies**

A primary full electronic search was performed on Primo Central Index = MEDLINE/PubMed, Taylor & Francis Online, ProQuest Business Collection, Scopus (Elsevier), OneFile (GALE), Social Sciences Citation Index (Web of Science), Science Direct Journals (Elsevier) Cambridge Journals (Cambridge University Press), Oxford Journals, (Oxford University Press), Springer Link, Taylor & Francis Online, Wiley Online Library, Sage publications (Sage Journals) and Emerald Insight. Citation searches and reference chaining were also completed on all relevant papers.

### **2.5.3 Grey Literature**

A secondary electronic search sought literature from; Alzheimer's Society, Dementia Journals/websites and Department of Health.

## **2.6 Stage 2. Deciding what is relevant to the initial interest**

This stage was used to focus the study by the selection of relevant studies and included a PRISMA flow chart – Figure 2 (Moher, Liberati, Tetzlaff & Altman, 2009) and the development of inclusion and exclusion criteria. Some of the inclusion and exclusion criteria was selected to aid me as a single assessor, evaluator, and the author of the synthesis – these included only English written papers, as I am English speaking only, and an exclusion of studies pre- 2000. I completed a scan search and found very few studies on the subject of intersubjectivity in dementia pre-2000 that were relevant to the meta-ethnography.

### 2.6.1 Selection of studies

Studies were screened according to Table 4 - inclusion and exclusion criteria. Dementia was defined as any known dementia diagnosis but did not include any cognitive impairment from other causes, such as acquired brain injuries, stroke (without further decline), learning disability, or any reversible cause for cognitive decline. Intersubjectivity was determined by any inter-relational or interpersonal connection between any person/people with a dementia diagnosis and another who was providing care or support to the individual/s.

Table 4 *Inclusion / Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
Original Qualitative Research English language written Journals People with a Dementia Diagnosis / Carer/s (including care providers) of people living with dementia Inter / subjectivity / interpersonal / relational aspects of intervention/engagement explored in the study Post-year 2000	Quantitative or Mixed Methodology Research (unless there are substantial qualitative findings) Non-Research articles (e.g. opinion pieces, editorials, policy papers) Non-English written papers Other Non-Dementia cognitive impairment No discussion of intersubjectivity / interpersonal/ relational aspects Pre-year 2000

### 2.6.2 Search Findings

Once repeat studies were removed, the combined collection of data base searches resulted in 1586 papers being identified. These were screened through a process of title and abstract review, leaving 48 articles which were shortlisted for a full content review; seven studies were selected. At this stage a reference list review and citation chaining was completed adding one more paper, providing eight studies which met all of the inclusion and exclusion criteria.

These findings are presented in Figure 2 by using a PRISMA guided flow diagram (Moher et al., 2009). I completed all of the reviews and selection individually, which



### **2.6.3 *Quality Assessment***

Each of the studies included in the meta-ethnography were assessed using the Critical Appraisal Skills programme (CASP) (CASP, 2018) to evaluate the clarity, design, methodology, rigour and reflexivity of the studies. However, most important to me as the researcher was that the findings were relevant to the overall synthesis (Tong, Flemming, McInnes, Oliver & Craig, 2012) and added clarity to my growing understanding of the subject of intersubjectivity in dementia. The main aim of the review was to establish if the studies were relevant to the aims of my meta-ethnography (Paudyal et al., 2018). In this case all studies included in the CASP evaluation were not only relevant but also valuable to my study's story development. Toye and colleagues (2016) disagree strongly with studies being included in meta-ethnography on their conceptual strength alone, noting however the difficulty in drawing a line of what is, or is not, methodological strong. As discussed in my introduction I did not want to eliminate studies purely on their weaknesses, but instead I wanted to look for their strengths. I am aware that this mindset somewhat questions the value of a quality assessment. To answer this my response is, although my time could have been used elsewhere (Campbell et al., 2011) I found the process extremely productive and conceptually enlightening (Toye et al., 2013). I did not exclude any studies based on the outcome of their quality assessment as there is no evidence to indicate that this improves the quality, or distorts the literature synthesis findings (Campbell et al., 2011; Dixon-Woods et al., 2007).

### **2.6.4 *Characteristics of all included studies***

Table 5 presents the main characteristics of the eight included studies. Three studies were completed in the UK, two in Australia, and the others across Europe. All the

studies had small sample groups, ranging from 2 – 42; with a sample collective of 141. All participants either had dementia, cared for someone with dementia, or had contact with people living with dementia through employment or voluntary work. As the meta-ethnographic synthesis focused on the presence of, and factors associated with intersubjectivity for people living with dementia, making connections between these aims and the studies chosen was imperative.

Stages of dementia within the chosen studies ranged from mild – severe, and all types of dementia were included. Some of the studies lacked detail on their participant/sample demographics, so a conclusive comment on age and gender mix could not be made. However, in seven studies those diagnosed with dementia were aged between their sixties to their nineties. The exception was Kelly (2008) where the two participants had a diagnosis of AIDS dementia and were younger. Across studies females were slightly more represented than males, particularly participants diagnosed with dementia which was the largest cohort across the studies.

All studies were qualitative in nature, seven of the eight used interviews as a main data collection method, the eighth used a focus group to seek participant perspective. Six of the eight studies observed participants, somewhat guided by their methodology; ethnography, grounded theory, and participatory research. On review, although there was a wide diversity of findings, I believed that all studies were relevant to the synthesis and had addressed issues of intersubjectivity in dementia care.

## **2.7 Data Analysis**

Analysis was completed using stage three to seven of Noblit and Hare's (1988) seven stages of a meta-ethnographic synthesis of qualitative studies, as shown in Table 1 (page 20) and as described in the stages 3 - 7 below.

## **2.8 Stage 3. Reading the studies**

Once the studies were selected, they were read and re-read several times. Studies were read in both hard and electronic copies and then characteristics were extracted. Once extracted the data was transferred to a Table (Table 5). Alongside data extraction I also appraised each of the eight studies at this stage using a 10 items quality appraisal tool shown in Table 6 (CASP, 2018). This tool records if criteria are met (satisfied), not met (not satisfied) or is not clear by recording a tick, cross, or not clear (N/C) symbol against the study for each of the 10 criteria. This provided a quick and easy read version of the tool that indicated the evaluated quality at a glance (Smith, Latham, Maskrey & Blyth, 2015). Harrison, Reid, Quinn and Shenkin, (2016) argue that the strength and appropriateness of the quality tool is its relation to the clinical practice in question and its ease of understanding. Nevertheless, it must be acknowledged that the tool does rely on a subjective judgement of the quality of the study, which does open the reviewer up to selection bias. However, no studies were eliminated at this stage and all studies selected were used for the synthesis. Initial themes, quotes, and findings were also highlighted during this stage to begin the process of first order construct development (Appendix 1 & Table 7).

Table 5 *Characteristics of all included studies*

<b>First Author</b>	Kalis et al (2005) (1)	Kelly (2008) - (2)	Svanstrom et al (2013) - (3)	Ullan et al (2013) - (4)
<b>Country of Study</b>	Netherlands	Australia	Sweden	Spain
<b>Setting</b>	Dementia-care wards	Residential Care	Nursing care	Day Centre Art Workshop
<b>Sample</b>	10 participants (Nursing Home care staff)	2 participants (living with dementia)	25 participants (mixed people living with dementia / spouse)	21 participants (living with dementia)
<b>Dementia Type</b>	Varied Dementia Types and varied stages	AIDS Dementia	Varied Dementia Types and varied stages	Varied Dementia Types - Mild-Moderate stage
<b>Methodology</b>	Grounded Theory	Ethnography	Hermeneutic	Exploratory Study
<b>Data Collection</b>	Observation & Interviews	Observation, interview & other media (drawing)	Phenomenological Interviews	Participant Observation / Focus group
<b>Role of Inter / Subjectivity</b>	Professional carer experiences of quality of life for the people they care for, including the role of subjectivity	The role of memory on inter / subjectivity	The role of intersubjectivity in the provision of care/nursing	The move from pathology-based care to person centred care utilising inter / subjectivity

Table 5 cont...

<b>First Author</b>	Boyle & Warren (2015) - (5)	Johnson (2016) (6)	Boyle (2017) -(7)	Marsh et al (2018) -(8)
<b>Country of Study</b>	UK	UK	UK	Australia
<b>Setting</b>	Home / local community	Care homes & community groups	Home visits	Community gardens
<b>Sample</b>	42 participants (21 living with dementia 21 spouses)	6 participants (living with dementia)	16 participants (living with dementia)	19 participants (4 living with dementia, 15 staff/volunteers)
<b>Dementia Type</b>	Varied Dementia Types mild – severe	Varied types Moderate dementia	Varied Dementia Types - Mild-Moderate stage	Varied Dementia Types and varied stages
<b>Methodology</b>	Ethnography & Creativity	Interpretative Phenomenology	Ethnography	Participatory research
<b>Data Collection</b>	Observation & Interviews	Interviews and performative (art) social science	Observation & Interviews	Observation, video & interview
<b>Role of Inter / Subjectivity</b>	Can intersubjectivity remain preserved in relationships when social skills are diminished	The role of intersubjectivity in the construction of identity in dementia	Can people living with dementia understand their relational self (intersubjectivity) as well as their subjective self	Can community garden / open space activity foster an active citizenship and develop relational intersubjectivity

Table 6 *Summary of the CASP critical appraisal criteria & results*

<b>CASP Critical Appraisal Criteria</b>										
1. Was there a clear statement of the aims of the research?										
2. Is a qualitative methodology appropriate?										
3. Was the research design appropriate to address the aims of the research?										
4. Was the recruitment strategy appropriate to the aims of the research?										
5. Were the data collected in a way that addressed the research issue?										
6. Has the relationship between researcher and participants been adequately considered?										
7. Have ethical issues been taken into consideration?										
8. Was the data analysis sufficiently rigorous?										
9. Is there a clear statement of findings?										
10. Is the research valuable to clinical practice?										
<b>✓, satisfied; x, not satisfied; N/C, not clear</b>										
<b>CASP Critical Appraisal Results</b>										
<b>Study</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Kalis et al (2005)	✓	✓	✓	✓	✓	N/C	✓	✓	✓	✓
Kelly (2008)	N/C	✓	✓	✓	✓	×	✓	×	✓	✓
Svanstrom et al (2013)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Ullan et al (2013)	✓	✓	✓	✓	✓	N/C	✓	✓	✓	✓
Boyle & Warren (2015)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Johnson (2016)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Boyle (2017)	N/C	✓	✓	✓	✓	N/C	✓	✓	✓	✓
Marsh et al (2018)	✓	✓	✓	✓	✓	✓	✓	N/C	✓	✓

## 2.9 Stage 4. Determining how the studies are related

By using information found in the studies during stage 3 and continuing into stage 4 participant quotes were identified and highlighted where there was a connection between the inter/subjective/relational/personal experiences of people living with dementia and those who cared for or supported them. These findings are shown in the first order constructs shown in column 1 of Table 7. These quotes are taken directly from the eight selected studies and are the words of the study participants. The studies in which they are found are numbered next to the quote. At this early stage it was noted that all eight studies provided quotes which were relevant to the assembly of a meta-ethnographic synthesis. A relationship was beginning to emerge between all of the studies. Each stage of this process will be discussed further in this section.

Table 7 *First, second and third order constructs*

First order Constructs (illustrative quotes) *Q = Quote	Second order Constructs	Third order constructs
<p><b>*Q 1:</b> “He is very happy sitting here ... he doesn’t want to go out, no.” (Boyle &amp; Warren, 2015 p.8) - (Study 5)</p> <p><b>Q 2:</b> The skills of people living with dementia are frequently underestimated... “it’s always good to learn”; “I didn’t expect to learn”; “I have really enjoyed it, each day we learned something” (Ullan et al., 2013 p.16) (Study 4)</p> <p><b>Q 3:</b> “This is a nice safe space where they can be active, where they can do things they’re probably really used to doing and be part of a conversation, part of an activity” (Marsh et al., 2018 p.176) - (Study 8)</p> <p><b>Q 4:</b> “It was individual...all the workshops were individual, the people did what they really wanted to do or said they wanted to do” (Ullan et al., 2013 p.17) - (Study 4)</p> <p><b>Q 5:</b> “We try to maintain and guarantee the physical freedom of movement of</p>	<p><b>Activity in dementia</b> (3, 4, 6, 7 &amp; 8) (meaningful activity, assuming capacity/ability, underestimating, risk versus benefit, social roles, community, choice, quality of life, independence)</p>	

<p>people...we are also willing to take certain risks in that, the risk that people fall as well". (Kalis et al., 2005 p.39) (Study 1)</p> <p><b>Q 6:</b> Referring to relationships... 'It's always different. You lose quite a lot when you've got dementia.'" (Kelly, 2008 p. 456) - (Study 2)</p> <p><b>Q 7:</b> "We love each other, don't we?... whereupon he affirmed: "Course we do." (Boyle &amp; Warren, 2015 p.9) - (Study 5)</p> <p><b>Q 8:</b> "when I love him, I love him; when I don't love him, I like him and when I don't like him, I love him". (Boyle, 2017 p.3) (Study 7)</p> <p><b>Q 9:</b> "...sitting there alone, you know, day in and day out, there is something terrible. I've never been alone all my life...I don't want not be a part of it anymore... my life can end now...it is enough now..." (Svanstrom et al., 2013 p.5) - (Study 3)</p> <p><b>Q 10:</b> "I don't like being lonely. I don't like that, because you sit and think." (Johnson, 2016 p.75) (Study 6)</p> <p><b>Q 11:</b> If someone could just sit with somebody in the garden what an ideal opportunity and environment to do that and just listen, that's all you have to do" (Marsh et al., 2018 p.176) -( Study 8)</p> <p><b>Q 12:</b> "If you've got a disease or something wrong, [people] shun you."- referring to dementia (Johnson, 2016 p.705) (Study 6).</p> <p><b>Q 13:</b> "we . . . try to connect to the feelings that people have . . . you estimate the feelings people have and what they need emotionally". (Kalis et al., 2005 p.39) (Study 1)</p> <p><b>Q 14:</b> "They will never sit down like this and talk to me; instead, they are running in and out and . . .and vacuuming and cleaning" (Svanstrom et al., 2013 p.6) (Study 3)</p> <p><b>Q 15:</b> Feeling valued, having meaningful roles, a feeling of belonging and contributing positively alongside others in the community... "I</p>	<p><b>Relationships in dementia</b> (1, 2, 3, 4, 5, 6, 7 &amp; 8) (meaningful, loving, social/gender roles, emotional, community, dis/trust, support, giving, belonging, othering, loneliness)</p> <p><b>Connecting with people and personhood in dementia</b> (1, 3, 4, 5, 6, 7 &amp; 8) (de/valuing, emotion, caring, supporting, guiding, neglecting, dismissing, meeting need, recognising strength, humanity, inclusivity)</p> <p><b>Communication in dementia</b> (1, 2, 3, 4, 5, 6, 7 &amp; 8)</p>	<p><b>Undervaluing the potential of people living with dementia = negative intersubjectivity</b></p>
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<p>think it's a sense of engaging in the community ... They love it" (Marsh et al., 2018, p.176 &amp; 178) (Study 8)</p> <p><b>Q 16:</b> "it's my own language that not everyone understands" (Ullan et al., 2013 p.17) - (Study 4)</p> <p><b>Q 17:</b> "I can get through to people if I say what I want... but some of them come up to me (and say) so-and-so and so-and-so-and-so. That confuses me a bit...". (Johnson, 2016 p.704) (Study 6)</p> <p><b>Q 18:</b> I'm sorry, I'm sorry...I never stop talking because I'm afraid I'll forget how to talk. Sometimes I wish my tongue was cut off so I had an excuse not to speak". (Kelly, 2008 p. 457) - (Study 2)</p> <p><b>Q 19:</b> "They joke with me to make me happy. They listen to me and make jokes with me and then you feel as you really are a human being." (Svanstrom et al., 2013 p.6) (Study 3)</p> <p><b>Q 20:</b> Her sociable nature was evident during the fieldwork as she was very chatty and cheerful...she commented: "Yes it is, yes it is the connection, the connection through the eyes" (Svanstrom et al., 2013 p.6) (Study 3)</p> <p><b>Q 21:</b> "I like people. I love people." (Boyle &amp; Warren, 2015 p.8) (Study 7)</p> <p><b>Q 22:</b> "I only like people that I like to know that they're kind, and that they're kind to other people." (Boyle &amp; Warren, 2015 p.9) - (Study 5)</p> <p><b>Q 23:</b> "We like to go out together. And I feel safer, because sometimes I get lost ... And I felt like a little boy, 'I want me mummy!' ... a man of six foot and I was, I was nearly crying". (Boyle, 2017 p.5) (Study 7)</p> <p><b>Q 24:</b> "I think my boys make me happy when they feel like it. Sometimes they make me sad, like at the moment they're not visiting me at all." (Johnson, 2016 p.705) (Study 6)</p>	<p>(Listening, talking, hearing, understanding, sharing, humour, engaging, struggling, helping)</p> <p><b>Reflexivity in dementia</b> (1,2, 3, 4, 5, 6, 7 &amp; 8) (Emotional, relationships, others, caring, feeling, connection, giving, sharing, understanding)</p>	<p><b>Relational engagement with people living with dementia = positive Intersubjectivity</b></p>
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### 2.10 Stage 5. Translating the studies into one another

I was at this stage able to determine that the eight studies included in the synthesis had produced reciprocal (similar) results. These are represented as five second order constructs shown in column 2 of Table 7. These second order constructs were; activity in dementia, relationships in dementia, connecting with people and personhood in dementia, communication in dementia, and reflexivity in dementia. These constructs were developed from the eight selected studies and are representative of the key words used by the authors in their articles. These key words are shown in brackets in column 2 Table 7 under each of the five second order constructs.

### 2.11 Stage 6. Synthesising translations

At this stage I returned to the eight selected studies and the highlighted and transferred narrative data (Table 7). All the study findings were read and reread to make sure that no data was missed, and all first and second order constructs were reviewed. All studies with reciprocal findings were recorded against the second order constructs. This was displayed by using the study identification numbers (Table 7 column 2) which openly indicate the reciprocity found across the selected eight studies. These key findings (first and second order constructs) were then translated into third order constructs. The two ‘found’ third order constructs (**‘Undervaluing the potential of people living with dementia equals negative intersubjectivity’** and **‘Relational engagement with people living with dementia equals positive Intersubjectivity’**) represent both positive and negative intersubjectivity experiences in dementia. These third order constructs were created by the combining study participants’ narratives, the study researcher/authors findings, and finally my synthesis of all the narratives/findings.

### **2.11.1 Reciprocal Findings**

Once data was analysed and synthesised the eight studies displayed an ability to translate into each other, leading to similar / reciprocal findings emerging. However, all people are different and live within their own beliefs systems and relational rules, so this needed to be kept in mind. “The relation between the two depends upon one fact; that the individual and the society are mutually dependent, one grows with the help of the other” (Hossain & Ali, 2014 p.130). The studies did however represent behaviours and beliefs which are likely to impact on intersubjectivity in dementia care. These intersubjective experiences are shown in the first and second order constructs (Table 7) and the barriers and gateways to intersubjectivity in the line-of-argument synthesis and conceptual model (Figure 3). The third order constructs developed and translated by the process of synthesis will be considered in the following section. First order construct quotes and second order key words will be used to represent the reciprocal nature of the findings, and also offer a reference source for the reader.

### **2.11.2 Third order constructs**

A third order construct combines the participants’ voices and the researcher/s interpretations to offer a new theory around a specific phenomenon through a reviewer synthesises (Lachal et al., 2017). In the case of my meta-ethnography the phenomenon addressed was the ability for people living with dementia to remain intersubjective, and if so, how would it present and be nurtured. These third order constructs (*‘Undervaluing the potential of people living with dementia equals negative intersubjectivity’* and *‘Relational engagement with people living with dementia equals positive intersubjectivity’*) are presented below, indicating the links and synthesis between the participants’ voices (first-order constructs) which are displayed as quotes (Q-

numerical). Second order constructs / interpretations /key words will be displayed in *italics*.

#### ***2.11.2.1 Undervaluing the potential of people living with dementia equals negative intersubjectivity***

Person centred and respectful *care* in dementia has a huge implication on the intersubjective responses care providers, or *loved* ones, may receive from a person living with dementia (Q11 & 15). This is likely to be negative if their ability to interact and *engage* is dismissed without question or reason (Q12 & Q14). Due to the nature of dementia people with a diagnosis will potentially have difficulty with *communication*, either expressing or *understanding* (Q16, Q18) (Ellis & Astell, 2017). Not recognising or *supporting* the person to *communicate* their wants and needs will not aid *relational engagement* and may well leave the person vulnerable and frightened (Q23). This form of *neglectful* behaviour can create a divide between the person living with dementia and their carer/supporter, which is unnecessary, and unhelpful (Q17). *Relationships* on an emotional level are always important in dementia (Q6, Q22 & Q24) and if *communication* is restricted, then emotional *engagement* is even more important (Q13, Q20 & Q21).

#### ***2.11.2.2 Relational engagement with people living with dementia equals positive Intersubjectivity***

Relationships as a whole are a key component of intersubjectivity, and as with any form of *relationship communication* can open up the opportunity to share *feelings* and thoughts, which may otherwise would go unsaid (Q7, Q8 & Q23). Without *relationships* many people living with dementia become *lonely and isolated* (Q10) and a *feeling* of

worthlessness (Q9), with no *meaning* to their lives. This does not need to be the case as many people living with dementia can *engage* in fun (Q19), person centred (Q4) and *meaningful* (Q3) activity which allows the person living with dementia to continue to be part of the *community* of which they *belong* (Q15). Often others feel they are doing what is best for the person living with dementia (Q1). However, by doing they can restrict them of their freedom in fear of reprisal (Q5). This limits their capacity to embrace new challenges and activities (Q2), which is often diminished when someone is diagnosed with dementia.

The approach of carers and those working with people living with dementia was indicative within the meta-ethnography findings. A common-sense statement perhaps, and yet people living with dementia are often dismissed as unable or unwilling to *engage with others* (Ellis & Astell, 2017; Clissett et al., 2013). The quotes below have been taken from some of the eight selected and synthesised studies, and offer suggestions which may well aid the creation of a more *inclusive* and constructive process of developing and maintaining intersubjectivity in dementia care;

“Viewing reflexivity as a socio-emotional (rather than a cognitive) process enables the agency of cognitively disabled people to be more readily recognised” (Boyle, 2017 p.6).

“Relationships between participants were characterised by a willingness to be respectful and by intentions to include and be included, rather than by prescribed professional or volunteer roles” (Marsh et al., 2018 p.177).

“we . . . try to connect to the feelings that people have . . . you estimate the feelings people have and what they need emotionally” (Kalis et al., 2005 p.39).

“Feeling valued, having meaningful roles, a feeling of belonging and contributing positively alongside others in the community. A meaningful existence is core to a sense of citizenship” (Marsh et al., 2018 p.178)

## 2.12 Stage 7. Expressing the synthesis

After all other stages were complete, and first, second, and the third order constructs were developed and reconsidered the synthesis of findings allowed for a new level of interpretation to be achieved. This is represented as a line-of-argument synthesis (Figure 3) which is depicted as a conceptual model of intersubjectivity in dementia which considers the barriers, gateways, and subsequent balance required to achieve positive relational and intersubjective experiences. This line-of-argument model represents a synthesis of the literature reviewed, and through an iterative process offers a combined and unabridged meaning (Feast et al., 2018) of intersubjectivity for people living with dementia.

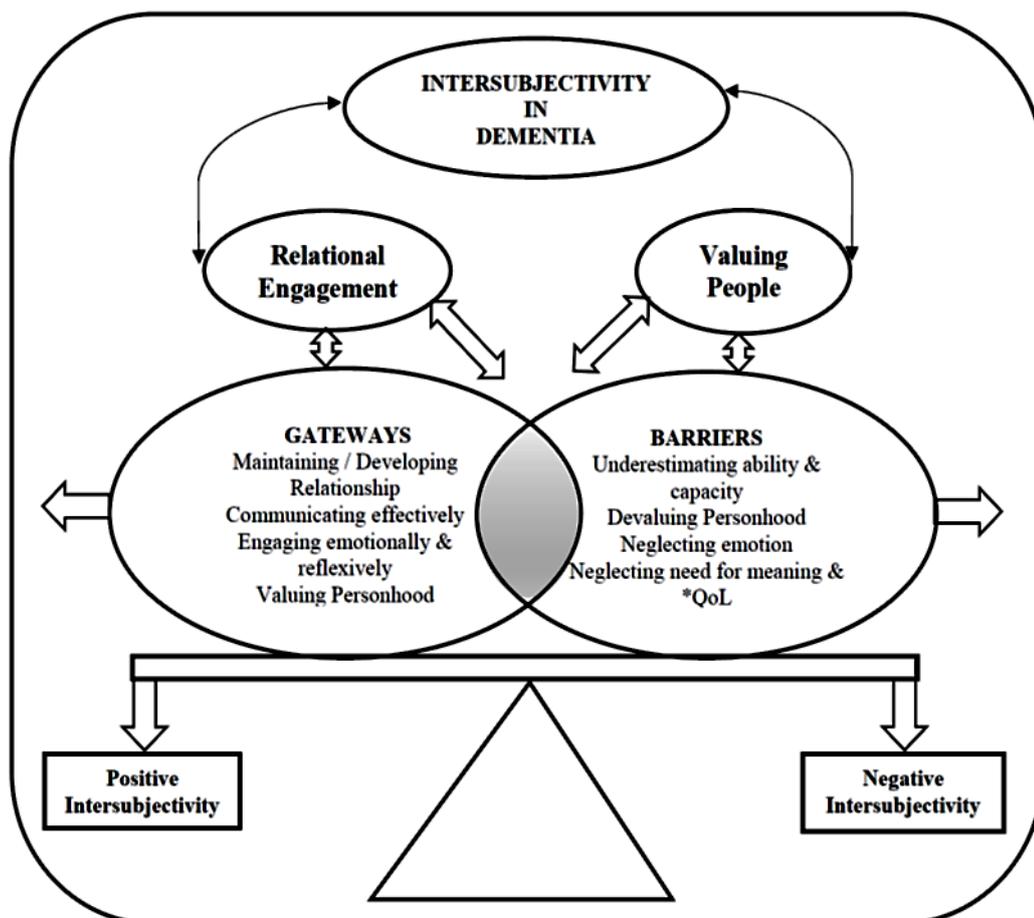


Figure 3 Line-of-argument conceptual model

\* Quality of Life

The eight studies analysed and synthesised concluded that the ability to be intersubjective remains for people living with dementia. If the person is respected as being “still there” (personhood) by the care provider “that necessarily includes his sense that the person is expressing feelings about their relationship (personness)” and therefore intersubjectivity remains (England, 2016 p. 964).

The synthesis of the studies displays the capacity for intersubjectivity to take place between both parties (often on an emotional level) if the key concepts found are met (achieving meaningful activity, relational connections made by valuing personhood, being reflexive and observing reflexivity, and communicating effectively). All of these require the person providing care to the person living with dementia to recognise their ability to communicate and connect on a positive emotional (and at times cognitive) level, through the valuing and honouring of the person living with dementia’s personhood. I must however reiterate that the line-of-argument conceptual model created by this process was not developed to use as a hypothesis in which to test or challenge my PhD study. It was created more for the purpose of a social or phenomenon explanation of intersubjectivity in dementia.

### ***2.12.1 Strength and Limitations***

I believe that by using meta-ethnography as a qualitative literature synthesis I choose an appropriate methodology in which to explore the subject of intersubjectivity in dementia care. I used recognised and established processes and tools to complete my literature synthesis such as the seven stages of meta-ethnography (Noblit & Hare, 1988), PRISMA (Moher et al., 2009) and CASP (CASP, 2018) which I feel guides and supports my PhD thesis aims and also compliments my thesis methodology (Autoethnography).

The process of a meta-ethnographical synthesis has the benefit of the result being of “greater than the sum of its parts” (Barnett-Page & Thomas, 2009 p.2) which was guided by the seven stages (Noblit & Hare, 1988). I have explained and recorded all seven stages openly to be transparent and allow the reader to see the source and process of the constructs developed.

In terms of limitations, I do need to acknowledge that my meta-ethnographic synthesis would have been aided by having additional study reviewer, quality reviewer, and perhaps another person to inform and support the construction of my line-of-argument conceptual model (France et al., 2019). This however could not be facilitated, and I propose that my findings would not have been identical to what other researcher/s may have concluded due to the iterative and inductive process of meta-ethnography (Barnett-Page & Thomas, 2009). Another limitation of the synthesis was the low number of studies synthesised (8). However, Noblit & Hare (1988) recommendations in their seminal text was between 2-6 studies (Toye et al., 2014). To find more studies I could have potentially proposed a wider search date window, however the aim of meta-ethnography was to achieve quality of synthesis, rather than be distracted by the quantity of studies selected (Toye et al., 2014).

### ***2.12.2 Theoretical and Care Implications***

The findings from synthesis of the eight studies will now inform my own PhD study by acting as a conceptual guiding light and a pathway in which to commence a new journey. The constructs and line-of-argument conceptual model developed from the synthesis very much aligns with Tom Kitwood’s (1997) person centred dementia care model, and the clash, or indeed balance between malignant social psychology and

positive person work in dementia. Much, as Tom Kitwood (1990) reported, and my synthesis indicates, achieving a balance between the barriers and gateways of relationality will lead to the potential of a more positive intersubjective and caring relationship. This in turn “opens up the way for a more personal and optimistic view of care giving” to emerge, where personhood is valued (Kitwood, 1990, p. 177).

I was somewhat surprised that the synthesis reached the conclusion it had, mindful that the selected literature was written long after Tom Kitwood’s death in 1997. The findings indicate that almost three decades on there is still a need for those caring for people living with dementia to look deep inside themselves and reflect on their own actions and behaviours. The ability to reflect and self-inquire in and on action (Boersma, 2012; Edwards, 2017) may go some way to answer the question of whether they as carers, or practitioners are a gateway or indeed a barrier to positive intersubjectivity in dementia care. This I feel is particularly captured in a quote I have taken from one of the studies included in the synthesis.

“In human existence, suffering is related to life itself or to different diseases that at times cannot be avoided, but when it comes to suffering related to care, the question of how this kind of suffering can be avoided remains” (Svanström, Sundler, Berglund, & Westin, 2013 p.2).

### **2.13 Conclusion**

My synthesis has concluded that people living with dementia continue to have the capacity to be intersubjective, if not always on a cognitive level on an emotional level (Boyle & Warren, 2017; Kalis, Schermer & Van Delden, 2005; Marsh, Courtney-Pratt & Campbell, 2018). Nevertheless, intersubjectivity by its very name and process is not

just one-way (Boyle & Warren, 2015; Burke, 2014) and requires other to engage. The findings indicate that it is of great importance that care providers, and those supporting people living with dementia, recognise that their own responses and behaviours towards a person living with dementia may influence the intersubjective outcome. The line-of-argument synthesis indicates that the person living with dementia may struggle at times with instructions and communication, and yet will still be able to intersubjectively engage with emotions. The fact that the person living with dementia will actively embrace value-based practice affords the care provider with a guide on how to achieve positive intersubjectivity. And, in doing so, it will aid the person living with dementia to be part of a meaningful community.

The findings in this synthesis are by no means a new discovery, and the changes required to provide positive intersubjective dementia care appear on a surface level to be achievable. However, stories of poor care, neglect, and mistreatment continue to emerge within dementia care. This perhaps emphasises a lack of investment from some care providers/services in forms of care that value relationships and personhood in dementia (Kadri et al., 2018).

As a prologue to my study story my meta-ethnography found sufficient evidence to indicate that the capacity for people living with dementia to be intersubjective is somewhat restricted, and a nurse's behaviour can have an impact on that intersubjective experience. To move this learning forward into my study, and offer a new chapter I need to explore the story further by narrating my experiences of intersubjectivity during moments of behaviours that challenge. To do this my study will question 'what was happening for me ('I')?' during my intersubjective relationship with people living with

dementia ('Thou') during moments of behaviours that challenge. And, in asking this I also ask how this intersubjective experience /connection / moment impacted on me as nurse, and the person living with dementia. Finally, I will also ask myself, would knowing this guide or influence my nursing support and treatment decision-making when presented with behaviours that challenge in dementia?

### **3 Chapter 3 - Introduction to becoming a study**

#### **3.1 Introduction to becoming**

My meta-ethnographic literature search found very little evidence of studies that have explored the relational impact of behaviours that challenge on the care relationship between the person living with dementia and the care provider/carer. In the case of my study the relational impact to be explored will be that of mine as a nurse, as I work with people living with dementia during moments of behaviours that challenge. Intersubjectivity is the sharing and movement of an energy between two subjects (Ben-Shahar, 2014), and therefore I also need to consider the person living with dementia in my narrative, and at times other professionals involved in their care.

This chapter will offer an introduction of me as a nurse ('I'); the story's (study) narrator. However, my study is not a biography it is an autoethnography, and therefore as discussed, the narrative will make connections with others providing care within the culture of dementia care, and of course the people living with dementia themselves. The characters of these stories, which at times will include me, will be both protagonists and antagonist depending on their position within the intersubjective experience described at the time. This chapter will therefore introduce the role of intersubjectivity within my study; an acknowledgement of the connection between self and other during behaviours that challenge moments.

My study will use and refer to metaphors and imagery throughout, two of which have become key to my study design, these metaphors are; the rhizome and the kaleidoscope. Both metaphors represent the fluidity and narrative temporality (Currie, 2013) of my story's construction, which is a key component of my study. Alongside metaphor, my study also refers to a Latin term, *in medias res* (translated as 'in the midst') in order to

suggest that the protagonists and antagonists of the intersubjective story are not starting a new chapter but are drawing on past chapters. The position and context of the metaphors and imagery within my study is described in more detail in this chapter. Due to the nature of my study's methodology (autoethnography) my thesis will be written and presented in the first person.

### **3.2 An introduction to 'I'**

I am a registered mental health nurse. I have been a qualified nurse for fifteen years; however, I also worked as a support worker previously so have accumulated 20 years of health care experience. Much of this experience has been with older adults with mental health difficulties and working with people who are considered challenging to others. I also have close family members who have required significant support, treatment, and guidance from health services, so I acknowledge that I also hold some carers lived experiences and perspectives.

The period of time in which my thesis concentrates is across four years where I worked in a large general hospital as a mental health liaison nurse. A significant part of my role was to educate others on the support and treatment of people with a dementia diagnosis who were presenting with behaviours which were considered challenging to others. Being in this role led me to consider why the subject of behaviours that challenge in dementia instigated such a variety of cognitive, emotional, and physiological responses and sensations within me, others, and of course the people I met living with dementia.

Whilst reflecting on my role I concluded that if I am to be in a trusted position of educating and advising others I should explore what behaviours that challenge is to me

as a person and a professional, and also explore the relationship between the two. I needed to do this before I could consider, or indeed understand the responses of other nurses and healthcare professionals when faced with behaviours that challenge in dementia. Therefore, I asked myself, what moments of behaviours that challenge had I experienced, and how had I felt? Where has my personal and professional understanding of behaviours that challenge developed from? Moreover, how did these experiences and understandings of the subject connect with others? I also wanted to consider if my experiences and understanding of behaviours that challenge influenced my decision making as a nurse (when I was supporting people living with dementia) and the advice I offered other nurses, healthcare professionals, and family members/carers.

### **3.3 Introducing intersubjectivity to my study**

As presented in my literature review section, *introducing intersubjectivity to my meta-ethnography* the theory of intersubjectivity I have chosen to use for my study is intersubjectivity as presented by Alfred Schutz, in the 1960s (Schutz, 1964; 1966). This theory posits that intersubjective experiences are experiences which are not only in “my world” but in the “world of all of us”. (Schutz, 1966 p.53). However, although I acknowledge that the experience is shared, I can only describe my own subjective state, i.e. my experiences and senses during moments of behaviours which challenge in dementia. Nevertheless, I have endeavoured to always represent “otherness” in my study (Glocer fiorini, 2016 p.1103). In doing so I offer transparency towards how and why other/s may have been or could be influenced by our/my (inter) subjective experience/s.

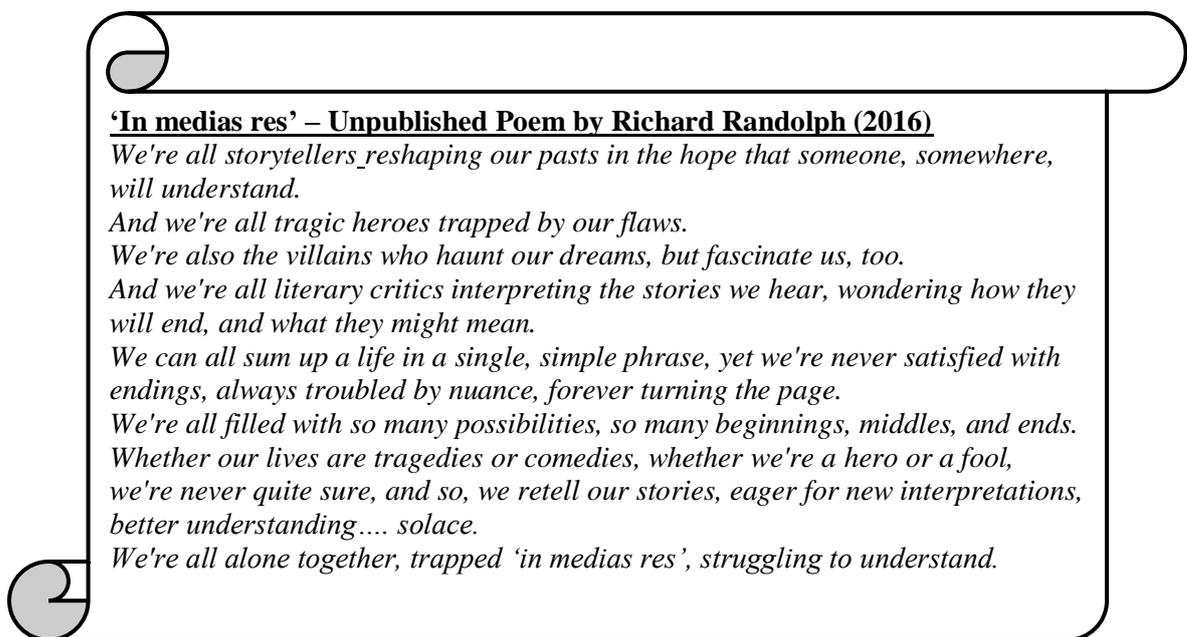
I wish to note at this early stage of my study that it is my belief that it is not only our past experiences of behaviours that challenge that influence intersubjectivity, but also our responses and behaviours in the intersubjective moment itself. These are the behaviours presented by the person living with dementia, but also the response behaviours of the nurse. Behaviour “is shared experience” and our experiences of “subjectivity is intersubjectivity” (Schutz, 1966 p.54; Trujillo, 2018 p.6).

### 3.4 **Introducing... *in medias res***

*In medias res* (Latin) translated as ‘in the midst of things’ (Collins English Dictionary, 2019) was taken from a passage in Horace's *Ars Poetica*. Horace (13BC) introduced the term in ‘*Ars Poetica*’, “*Semper ad eventum festinat et in medias res non secus ac notas auditorem rapit, et quaeperate tractata nitescere posse relinquit*”. This translated into English is, “even he hastens to the issue, and hurries his hearer into the story’s midst, as if already known, and what he fears he cannot make attractive with his touch he abandons” (Fairclough, 1961 p.462–463).

I chose to use the term *in medias res*, referred to in my study in its translated form ‘in the midst of’ as it is a term used to express an understanding that stories can, and often do start in the middle. I believe this is the same for intersubjectivity, due to the pre-formed ‘I’ stories brought into the intersubjective moment. Whilst reflecting on story formation I was particularly struck by one part of the translation, “hurries his hearer into the story’s midst, as if already known” (Fairclough, 1961 p.462). This extract represented that not only is my study a representation of the ‘story’s midst’, but so is the moment where I as a nurse meet the person living with dementia presenting with behaviours that challenge. And, in the midst of that story I as the nurse could be at risk

of reaching a conclusion of the ‘already known’. Mindful of this, I also cannot assume the readers’ experiences of these moments will be the same as mine. We are all in a different middle with differing narratives of what is already known, or at least believed to be known. To support that narrative, and to express the initial difficulty I had interpreting the meaning of *in medias res* (in the context of my study) I offer an unpublished poem written by Richard Randolph which succinctly describes that narrative struggle (Figure 4).



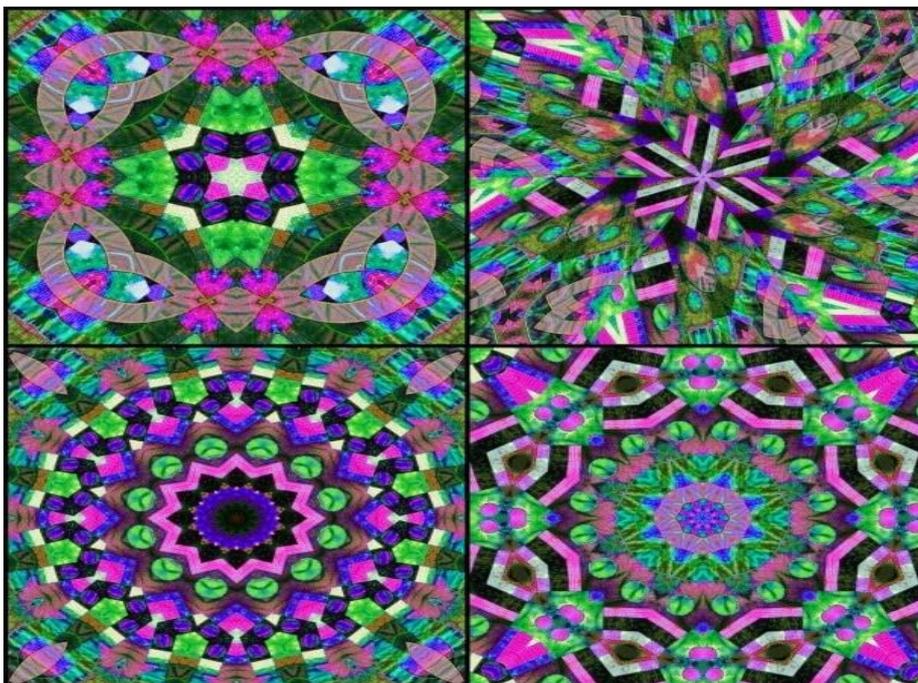
*Figure 4* Poem: In medias res

### 3.5 Introducing the Kaleidoscopic

To expand on the idea of my study capturing a transient moment in time I will refer to the idea of my thesis being a kaleidoscopic image; a point mentioned by one of my supervisors in my draft thesis feedback.

“It reminds me of a kaleidoscope – you can stop and create a pattern and describe it, but you could also turn the tube and create new patterns, ad infinitum...” (K.F. Thesis feedback, 2018).

My thesis aims to capture and explore brief moments in time in which I describe intersubjectivity between me as a nurse, and a person living with dementia; at a place where our combined stories meet. Each intersubjective exploration and sense making moment are a turn of the kaleidoscope where a new pattern is presented as the two of us interact. However, it will also become a new image each time the moment unfolds; just like the kaleidoscope when it is shaken, tapped, or turned again (Figure 5).



*Figure 5* Differing Kaleidoscopic images from the same Kaleidoscope

### 3.6 Introduction to my study

I always knew from the beginning of my PhD in Mental Health thesis journey the subject I wanted to research. Nevertheless, how, and whether I could, were completely different questions. I consider myself a visual learner, and knowledge sharing for me is

performed by the creation and the telling of stories in which we have either a mind's eye or visual representation of the story being told. With this in mind I have represented the commencement of my thesis in the form of a self-portrait sketch (Figure 4).

In my mind's eye I have an idea what I think I look like, and how I might be represented. Much like I do for my thesis. However, an artist will talk of their vision and mind's eye as precursors of their masterpiece, but without the studio, canvas, paint and brushes, and of course experience and ability, there is no creation (McGraw, 2012). Below (Figure 6) is the preliminary sketch which I created as part of my thesis.



*Figure 6* Self-Portrait Sketch

I hope that as my knowledge grows and I became more aware of my own subjectivity so will my self-portrait, as it develops alongside my study. It is my intention that not only will the oils on canvas produce a self-portrait, but my thesis will also be a form of self-portrait. The paper on which I type is my canvas, the keyboard is my brush, the words are my paint, and my thesis will be a narrative self-portrait.

As discussed in my '*introduction to I*' section I would often ask myself where did I belong within my chosen study subject, and how was I going to explore not only the subject but also my position within the study (Pitard, 2017). This period of finding my place in the study led to a series of false starts, a variety of proposed beginnings and ends, followed by elation at success, only to be marred by a feeling of frustration as it just did not feel right. I knew deep down inside that the methodology I was initially engaging with (Action Research) did not match the aspirations for my study. Much like my painted self-portrait, my narrative self-portrait was to emerge from a series of rubbed out images and ideas.

I wanted to explore how 'I' became interested in the subject, my story, and my connections between my personal life and the cultures in which I clinically worked. In doing so I aimed to develop a sense that knowledge that is created through experiences; a discovery that takes place within the communities we reside (Lawrence-Wilkes & Ashmore, 2014). I also wanted to explore my position without the limits and constraints that some forms of methodologies would bring; often as a side effect of their drive for objectivity (Jackson & Mazzei, 2008 p. 299). This is where and when (following an early stage conversation with my PhD supervisors) I discovered autoethnography as a methodology I could work with. The methodology made sense to me, and it allowed me the opportunity to experientially explore my subject as it allowed me to, "experience an experience" (Ellis, 1993 p.711).

I knew that telling my story was always going to be challenging (Wall, 2008) as I would not only be addressing professional times of challenge, but also personal experiences. However, I felt that to be truly congruent I had to explore all of me in order to make the

lived experiential connections between me as a nurse and the people living with dementia who I supported in my nursing role. This would also allow me to have a space in which to reflect on how I experienced and understood behaviours that challenge, which perhaps could be somewhat cathartic (Price, 2017).

Most importantly, I believe that my chosen methodology will allow me the opportunity to produce a thick description of my understanding and experiences of behaviours that challenge in dementia, by making connections between my personal and professional ('I') selves and people living with dementia ('Thou') (Buber, 1970). I will be considering the subjective self within the intersubjective experience/moment. Mead & Morris (1934 p.135) describe "self" as a phenomenon outside of the "physiological organism", which is made up of social experiences, activities, and relationships which are individual, yet influenced by others. Therefore, these methods of narrative examination will not only explore my developing story of behaviours that challenge but will also make connections between my personal and my professional experiences, in addition to the wider cultural nursing narrative (Ellis, 2004; Ellingson & Ellis, 2008; Ellis, Adams & Bochner, 2011). In doing so it is my hope that I will make connections between the "I" (nurse) and "Thou" (person living with dementia) in dementia care (Buber, 1970 p. I) during behavioural moments that have challenged 'us'.

To produce my story of intersubjectivity 'in the midst of' behaviours that challenge I will retrospectively explore my personal and professional (nurse) memories, experiences, and understandings of behaviours that challenge in dementia by collecting *ex post facto* and autobiographical data using retrospective reflexive practices. These retrospective reflexive reflections will explore the role of both my personal

(experiential) and my nurse (adapted) constructed self-identities (Kitwood, 1997). Personal (experiential) autoethnographic data collected from memory will consider and explore all personal life cycle events where I have perceived (my/others) behaviours to be challenging and have therefore influenced my understanding of what challenging behaviour is. However, from a nursing perspective (adapted) I will limit my data collection to retrospective reflexive accounts of behaviours that challenge moments that took place in a period of four years where I worked as a mental health liaison nurse in a general hospital.

Once the data is collected it will be analysed rhizomatically (Deleuze and Guattari, 1987) to create a study that is an intersubjective exploration of what occurred between me as a nurse and a person living with dementia when we are presented with behaviours that challenge. To acknowledge that my experiential data is retrospective (past), and yet makes connections with the present and the future my study will be framed within a Deleuzian theory of time (Deleuze, 1994). This theory of time suggests that our pure past, meets a living present creating a transient becoming future synthesis; creating a space where “I am affected by thought that is both mine and the thought of an Other” (Deleuze, 1994; Deleuze and Guattari, 1987; Voss, 2013 p.196).

### **3.7 The aims of my study**

1. To make sense of my (first-person) experiences of intersubjectivity in the midst (*in medias res*) of behaviours that challenge in dementia.
2. To understand whether my experiences of behaviours that challenge have influenced my decision making or capacity to support a person living with dementia during challenging moments.

3. To consider how I as a nurse can manage the intersubjective dynamic that arises in the midst (*in medias res*) of behaviours that challenge in dementia to achieve a positive outcome for both parties?

### **3.7.1 Objectives**

To produce a narrative (story) that will explore and share my experiences of intersubjective relationships between a nurse ('I') and people living with dementia ('Thou'), during times when I, Thou, or others, have found behaviours challenging.

## **4 Chapter 4 - Methodology and Design**

### **4.1 Introduction to chapter**

This chapter will introduce my study methodology and design, as well as my underlying philosophy, ontology, and epistemological standpoint. This changed between my original proposal and actual study development. This happened as I grew into my study and it became not only an academic process, but also a process of self-discovery and an exploration of otherness. In this chapter I also discuss my methodological reasoning and decision making in relation to my thesis methodology, and my choice to use autoethnography in the form of a layered account. I conclude the chapter by introducing the rhizome, rhizomatic mapping (Deleuze and Guattari, 1987) and my proposed rhizomatic study plan (Figure 8).

### **4.2 Study Methodology and Design**

Having reviewed the literature around the subject of intersubjectivity for people living with dementia I concluded that there was evidence that the ability to be intersubjective remains present, even during the latter stages of dementia. However, there is also no question that a sense of self and one's relational experiences are impacted on by the cognitive deterioration process of dementia (Hampson & Morris, 2016; Simm, Jamieson, Ong, Garner, & Kinsella, 2015). In concluding this, I noted that this places some reliance on care providers interpreting and understanding the potential underlying trigger factors of behaviours that challenge, many of which are emotionally driven. Having established this, I was contented that my study could now address its aims of making sense of my (first-person) experiences of intersubjectivity in the midst of behaviours that challenge in dementia, understand whether these experiences of have influenced my treatment/support decision making, and how 'I' as a nurse could manage

the challenging intersubjective dynamic to achieve a more positive outcome for both parties.

### **4.3 Epistemological and Ontological Introduction**

Much like my chosen methodology, discovering my ontological and epistemological position was also a journey of unearthing meaning. At the proposal stage of my thesis I decided that my study would be underpinned by a relativist ontology, an interpretivist philosophical theory, and a constructivist epistemological paradigm. This set of paradigms was formed by believing that truth and meaning is constructed by subjective interactions with the world, and by the schemas and values that people live by (Cohen & Crabtree, 2008; Gray, 2014; Ramey & Grubb, 2009; Yanow & Schwartz-Shea, 2011). However, the more I engaged with my thesis the more I moved away from conventional poststructuralist ontologies. For me the journey of ‘becoming’ became more important than the destination (Deleuze & Guattari, 1987).

This new becoming (Deleuze & Guattari, 1987) moved my ontological position from a position of predisposition and a single linear process, towards plurality of thought (Turner, 2011). This allowed me to open up and embrace other (Newman, 2003), giving me the capacity to learn from a process of continual convergence and conjoining (Deleuze & Guattari, 1987; Parr, 2005). To learn something new requires the ability to evaluate experiences and create new meanings as we enter, leave, and re-enter the unknown (Deleuze, 1994; Semetsky, 2009). Pitard, (2017) argues that what we know and how we know is not dependant by our ontology, or our epistemological belief system, but instead is a consequence of our life cycle and learning. I will explore this further in this section, and why I felt a Deleuzian theory of knowing was somewhat an

epiphany for me. I was now able to replace “identity” with “difference” and “being” with “becoming” through a process of “immanence”; “a fully immanent qualitative inquiry would have no “outside” or finality meaning” (Deleuze, 1994; Deleuze, 2001; Hein, 2018 p.89; Weinbaum, 2014 p.1). It is my proposition that by following a pluralistic ontological theory I can make micro-connections between my personal experiences of behaviours that challenge, and people living with dementia who present with behaviours that challenge.

#### **4.3.1 *My ontology and epistemology***

Ontology is the study or metaphysical understanding of what constitutes the nature of being or identity (Nayak & Chia, 2011). As discussed, my study does not aim to seek or prove the nature of being, but instead aims capture a journey of becoming. This process of discovery moved me towards, and connected me to, a sense of identity that is represented by a Deleuzian relational ontology and a future-oriented epistemology (Deleuze, 1994; Semetsky, 2004; Semetsky, 2011; Thiele, 2016; Weinbaum, 2014). This is what Deleuze refers to as Transcendental Empiricism (Deleuze, 1994; Deleuze, 2001). Deleuze questioned the predisposed and binary simplicity of previous philosophers’ narratives and belief systems that propose that thinking is based purely on seeking right from wrong; always in an attempt to find an indisputable truth (Deleuze, 1994). This form of thinking pre-assigns an order to subjects and objects (‘us/I’ and ‘it’) which is often not questioned and therefore is followed blindly (Buber, 1970; Dronsfield, 2012).

Creating a thesis that represented a relational ontology and future-oriented epistemology required me to intensely submerge myself into my deepest thoughts. I

needed to come face to face with pre-conceived perceptions; feel them and hear their very nature in order to know what they asked of me (Deleuze, 1994). In order to do this, Deleuze believes that we should first consider and embrace difference (Deleuze, 1994). However, instead of forming arguments that measure difference by our identity and comparison to others, we should instead recognise that there are multiple differences within oneself (Cockayne, Ruez, & Secor, 2016; Deleuze, 1994; Nayak & Chia, 2011). By identifying that there are conceptual differences in “all things” we can “break free of the shackles” which promote a way of being that is represented by “identity, opposition, analogy and resemblance” (Deleuze, 1994 p.29 & 262). This promotes a form of thinking that does not seek uniformity, but instead is fascinated by nuance and diversity within our culture/s. This form of thinking also offers a narrative that promotes a sense of belonging, rather than seeking the exclusion of other due to perceived subjective or objective differences (Bignall, 2008; Deleuze, 1994).

In my study, I am working from an ontological and epistemological position that those identified as, and representing people living with dementia, are not different from me. They are instead connected to me through a transcendental form of thinking, multiplicity of lines and open connections which have been instigated by the moments in which we connect (behaviours that challenge) (Deleuze, 1994; Deleuze, 2001). These moments will allow new ideas and becoming to emerge (Deleuze & Guattari, 1987; Semetsky, 2004) through an “eternal return” (Deleuze, 1994 p.52).

Deleuze argues that the stop/start process of becoming is not one stimulated or measured by the obvious divisions between individuals and events, but instead by diverse and dynamic movements in space and time (Deleuze, 1994; Thiele, 2016). Time for Deleuze

(1994) is based on the syntheses of three phases: passive or habit, active or memory, and the new or future (Williams, 2011) represented by Deleuze's theory of time (Deleuze, 1994; Voss, 2013). In the case of my study, this is where a becoming has the potential to arise during moments that are both mine and others; both retrospective and in the here and now.

To address the aims of my study I needed to move from a passive idea of what intersubjectivity might be during moments of behavioural challenge, towards an active and actualised understanding. An understanding guided by a belief that our pure past, meets our living present, which in turn creates a transient synthesis of our becoming future (Deleuze, 1994). This allowed my study to move from the potential of a passive, pre-conscious, descriptive, and intrinsic ideation of what happens in the intersubjective moment of behaviours that challenge in dementia, towards an active, actualized, and self-conscious concept of these moments (Deleuze, 1994; Williams, 2011). The knowledge created by this travel through time is facilitated by repetition, and by the making and breaking of connections between me and person living with dementia during multiple moments of behaviours that challenge (Deleuze & Guattari, 1987).

According to: "Deleuze... we are travelling back and forward in time all the time.... For him, past, present, and future are not separate parts of time. Instead, they alternately treat each other as dimensions, where to be a dimension means to be a subsequent process" (Deleuze, 1994; Williams, 2011 p.8 & 9).

#### **4.4 Introducing Autoethnography**

Autoethnography is a form of qualitative research methodology that systematically analyses personal lived experiences in order to understand cultural experiences (Ellis,

2004; Ellis et al., 2011). In the case of my study, the cultural experience I will explore is my role and position as a mental health nurse working in a general hospital. The lived experiences I will explore are my personal and professional experiences of behaviours that challenge. My aims through my study are to understand my experiences as a nurse, but also make connections between those supporting people presenting with these behaviours, and those experiencing these behaviours.

Some consider autoethnography as weak, introspective, self-indulgent, and an egotistic method of writing (Allen-Collinson, & Hockey, 2008; Denshire & Lee, 2013) arguing that it sits on the outskirts of academia and qualitative judgements (Holt, 2003). However, autoethnography (and 'I') do not apologise for embracing and exploring subjectivity (Maréchal, 2010) as the process of self-exploration; as reflexivity is far more than a surface glance (Ellis, 2004). Most importantly, autoethnography requires storytelling and a “narrative inquiry that can provoke identification, feelings, emotions, and dialogue” (Maréchal, 2010 p.45) offering a cultural meaning to the reader. This is facilitated through a combination of ethnography, biography, and self-analysis, making connections between self and others within a social, political, and cultural context; a coalition of self and others (Chang, 2007; Ellis, 2004; Ngunjiri, Hernandez, & Chang, 2010).

Advocates of this qualitative research methodology (Anderson, 2006; Chang, 2008; Denzin, 2006; Ellis, 2004; Ellis & Bochner, 2000; Vryan, 2006) describe autoethnography as research method which illuminates social phenomenon through the emersion and analysis of self (Chang, 2016; Ngunjiri et al., 2010). It is a method of writing which embraces an intertwined process of data collection and analysis, where

the text and the author are as one; ultimately maintaining an internalised authenticity (Alvesson and Skoldberg, 2012). Autoethnography principally has two methods, one of which explores and experiments with personal reminiscence narrative (evocative autoethnography) (Anderson, 2006; Donovan, 2011) and the other adhering more readily to academic expectation (analytical autoethnography) (Anderson, 2006; Chang, 2008). However, these methods can be combined (Wall, 2008).

#### **4.4.1 *Evocative Autoethnography***

‘Imagine they want to write stories with raw and naked emotion that investigate life’s messiness, including twists of fate and chance’ (Bochner & Ellis, 2016, p. 10).

The form of autoethnography produced is very much reliant on the author’s writing style, and story they wish to tell (Chang, 2007; Ellis et al., 2011). An evocative autoethnographic account is a highly personal story, so is more likely to focus on the ‘auto’ than formal research convention (Wall, 2006). This allows the reader to make their own mind up on its relevance to them, or the wider society (Wall, 2006). However, some argue that research is not meant to be experiential and should always be analytical (Anderson, 2006; Atkinson, 2006; Duncan, 2004). Farrell, Bourgeois-Law, Regehr, & Ajjawi, (2015) disagree, and believe that evocative narrative should be endorsed in research in order to explore, feel, and experience what may be behind a social theory; promoting a lived experience voice within research (Allen-Collinson, 2012; Ellis et al., 2011).

Evocative autoethnography demands that meaningful storytelling and self-discourse are central tenets of its process to promote transformative learning through the use of attentive and creative writing (Bochner & Ellis, 2016). Even critics of the evocative

style of writing acknowledge the “considerable narrative and expressive skills” required to write in this style (Anderson, 2006 p.377). It however requires discipline, deep self-discovery, and critical reflexivity (Sambrook, 2015; Wall, 2008); “acknowledging the relationality of the researcher with the research” (Patnaik, 2013 p. 102) and the potential of subjectivity.

#### **4.4.2 *Analytic Autoethnography***

The five key features of analytic autoethnography according to Anderson (2006) are complete member (insider) researcher, analytic reflexivity, researcher’s self-narrative visibility, a dialogue with external informants, and a commitment to theoretical analysis. My study does not meet all of Anderson’s (2006) expectations for an analytical study as I have not used external informants. Vryan (2006) argues that the inclusion of others is not a prerequisite for an analytical autoethnography, as the viability and value of the external data still relies on the researcher’s interpretation. Nevertheless, even though I do not use external informants I do have a dialogue with them within my text. Many of Anderson’s expectations are included in my study, such as the use of analytical reflexivity, which I commit to throughout my narrative. I also present a clear and transparent self-narrative within my study. Some argue that using these fixed standards can restrict the researcher from using autoethnography effectively (Denzin, 2006; Vryan, 2006). Whilst others remain proponents of a pre-determined and structured framework (Chang, 2008).

I am comfortable with my autoethnography having a self-inquiry/self-researcher focus as I feel this form of self-discovery sits within the boundaries of autoethnography as a methodology as long as it speaks to the adjoining culture. “Researcher only”

autoethnography can be analytical as long as the study is not immersed in self-rhetoric and data collected produces an organised “authentic narrative” and “meaningful account” (McIlveen, 2008 p.4). My study focuses on data collection and analysis formed through “reflexive self-awareness” (Muncey, 2010, p. 16) as a “process of generating critical consciousness” (McIlveen, 2008 p.6). This offers an academic contribution to the subject of behaviours that challenge as a nurse, but also aims to evoke emotion and reflection in the reader. I therefore bring in elements of both evocative autoethnography (Ellis & Bochner, 2000) and analytic autoethnography (Anderson, 2006). These are merged through a “layered account” autoethnography (Ronai, 1992; Ronai, 1995 p.395) which is guided by process of rhizomatic analysis and mapping (Deleuze & Guattari, 1987).

#### **4.4.3 *Layered Autoethnography***

This methodological approach to autoethnography will be used to produce a study that makes connections between my story (auto), the wider group of nurses/healthcare professionals supporting people living with dementia, and those presenting with these behaviours (ethno/culture). However, to be a layered autoethnographic study I will also need to make connections between my found retrospective narrative data and the relevant evidence base (graphy). In the case of my through a process of systematic rhizoanalysis (Ellis, 2004; Ellis et al., 2011; Grant, 2009). This requires movement between, around, and through my multiple narrative inquiries (Chang, 2008) and reflections, making connections and relationships with the relevant literature and theories; producing a “layered writing interspersed with the voices of silenced others” (Denshire, 2013 p.8). These are displays of “multiple layers of consciousness” (Ellis, 2004 p37; Kelley, 2014) where a personal consciousness is explored and connected to

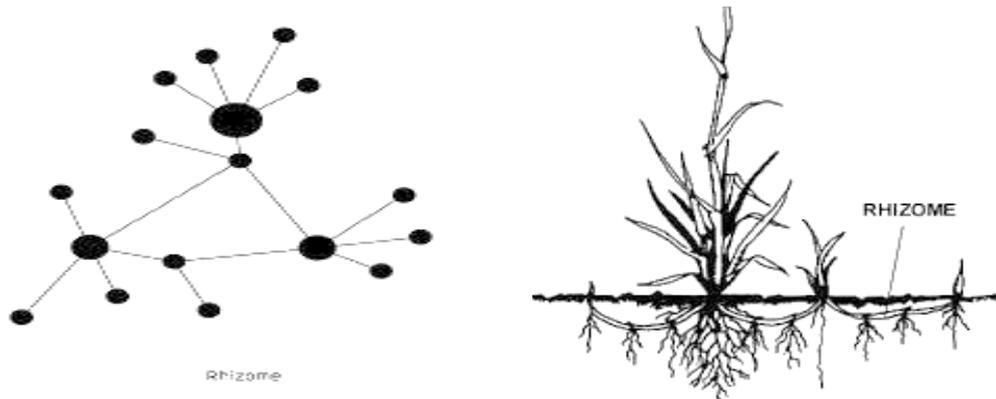
a wider cultural consciousness (Ellis & Bochner, 2000). This form of autoethnography allows me the flexibility to open my mind to emotional and evocative memories, share them with others, but also offer a structure and synthesis in which the ‘graphy’ of autoethnography is not forgotten (Wall, 2008).

#### **4.5 Rhizomatic mapping (*Deleuze and Guattari*)**

Much like other aspects of my study, I began with an aim to follow a conventional PhD chronological layout; fighting to fit in with the academic norm at all costs (Weidman & Stein 2003). However, this form of writing would not allow my and other/s voices to be heard, which left me feeling incongruent and empty (Kortenaar, 2013). This feeling of incongruence towards my study changed when I began to collect narrative and other media data, as I noted whatever data arose it was always connected. This opened up an opportunity to analyse what these connections were. The data collection was becoming my/our personal/professional reflexive recollection and story of behaviours that challenge in dementia. Therefore, the analysis needed to be able to take that eclectic data and find the story by mapping points within. How this could be done was not initially obvious. However, when I looked closer at the data, and my thoughts associated with the data, they were always connected. This is where I discovered and decided to use rhizoanalysis in the form of rhizomatic mapping (Deleuze & Guattari, 1987) to plot my story map.

This form of unpredictable, and perhaps somewhat disorganised plotting has been described as a rhizome (Deleuze & Guattari, 1987) and is created by the mapping of multiplicity. Deleuze (1988) described the qualitative process of multiplicity as virtual, subjective, and powerful; forces that cannot be counted which are experienced during

lived moments (Tampio, 2010). This process of mapping (Figure. 6) has multiple uses, and when used correctly, “a rhizome becomes a map to collect, analyze and report data” (Masny, 2013 p.342) through a series of heterogenic non-linear connections, creating a diverse and indiscriminate form (Deleuze & Guattari, 1987). A rhizome is named after underground plant bulbs and stem structures, which include the Iris (Figure 7).



*Figure 7* A Rhizome as a Methodology and Plant form.

This process of rhizomatic mapping (Deleuze & Guattari, 1987) allows my study’s methodology, data collection, and analysis to merge and mesh by allowing differences and similarities to evaporate, develop new ideas, and allowing old ideas to be *reformed* and *reimagined* by way of *re-embodied* (Strom & Martin, 2013). Honan and Sellers (2006) suggest that allowing this process to take place requires three connections: first, writing a rhizomatic text, second using rhizomatic thought, and third connecting and linking disparate forms of data. The data collected and presented in my study is therefore a response to this rhizomatic process, where the outcome of relationship is unknown, unpredictable, and is formed iteratively and organically (Masny, 2014; Deleuze & Guattari, 1987) through a future-oriented epistemology (Semetsky, 2004; Semetsky, 2011).

#### 4.6 Rhizomatic Study Plan

Figure 8 below is a representation of the rhizomatic-mapping pathway I will take in my study (Deleuze & Guattari, 1987). The map incorporates my epistemological and ontological position, my methodology, data collection, and analysis methods, and finally a sense making process that will be used to create my narrative (story) maps. These maps will aim to support my study to make sense of my (first-person) experiences of intersubjectivity in the midst of behaviours that challenge in dementia, understand whether these experiences of have influenced my treatment/support decision making, and finally how ‘I’ as a nurse can manage this intersubjectivity to achieve a positive outcome for both parties. These multiplicities of connections will eventually make up an “assemblage”, which will be my thesis as a whole (Deleuze and Guattari, 1987 p.3).

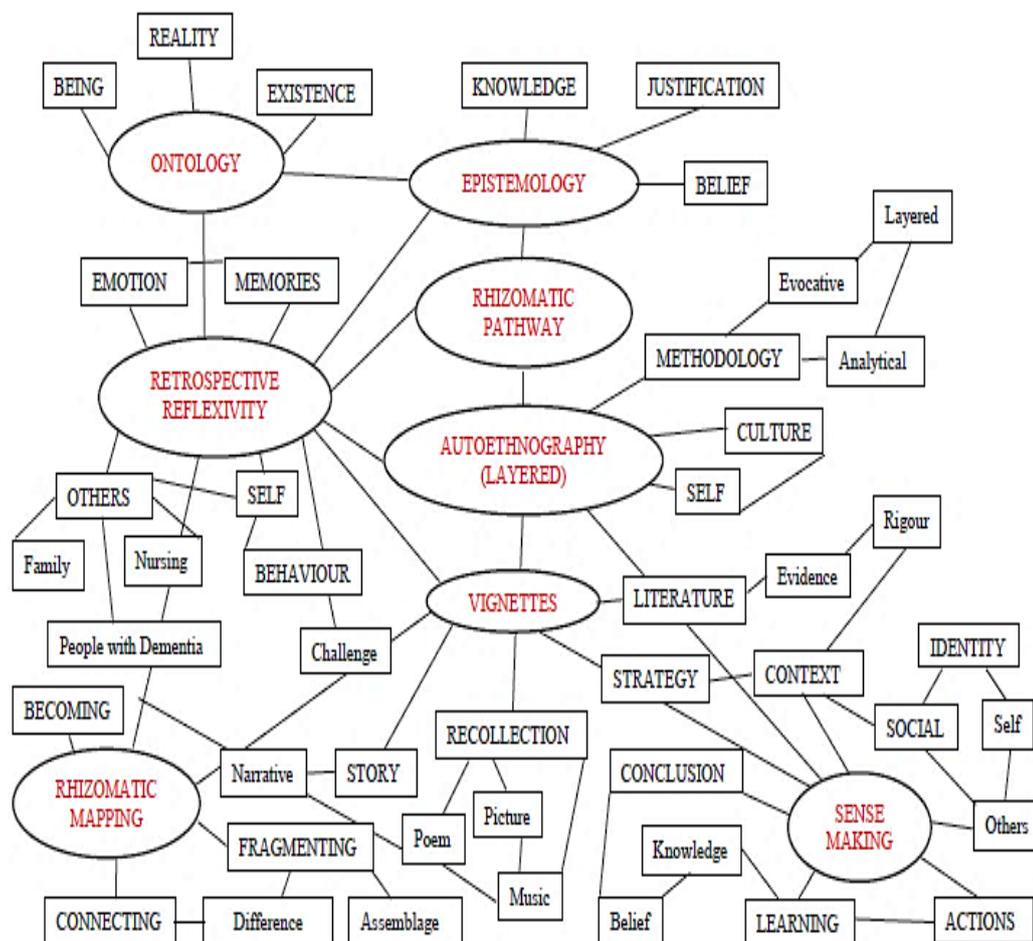


Figure 8 Rhizomatic pathway of my study process

## **5 Chapter 5 - Method and Ethical considerations**

### **5.1 Introduction to chapter**

The first part of this chapter will introduce what forms of autoethnography data have been collected (with examples), how that data was managed, and also how it has been analysed through a rhizomatic methods of mapping. I will briefly introduce the reader to retrospective reflexivity and its importance in collecting and analysing self-inquiry data. I will present my data management process in a tabular format. The data management process used is a combination of established methods of data management that have been developed to support both autoethnography and rhizoanalysis. I believe this offers transparency and clarity to the methods used in the data management of my study. Finally, this chapter considers and addresses key ethical issues through autoethnography ethical guidelines which have been based on a guideline used by Sikes (2015).

### **5.2 Becoming data...**

My reflexive data collection was completed during periods of self-protected time, which I allocated for that purpose. There were some occasions when music, a picture, or an event, would trigger a memory or a thought spontaneously. However, although these were recorded as data they were not reflected upon until a protected and safe time was available. At the beginning and the end of each period of reflection I completed a short period of mindfulness. This allowed me to be present in the moment (Edwards, 2017) and aware of the thoughts and feelings that I was experiencing whilst gathering data (Siegel, 2007). It permitted me to “live and learn” within the moment and then close my retrospective session down safely, and self -compassionately (Pensoneau-Conway, Adams, & Bolen, 2017 p.24; Vermersch, P. (2009). Mindfulness practice is promoted

by some in healthcare settings as part of clinical (nursing) supervision as it can aid clinicians to face challenging periods of critical self-talk or difficult memories (Barratt, 2017; Berry & Patti, 2015; Stanley, 2013).

In order to be mindful, and in turn support my data collection, I visited local green and blue spaces (moor, coastal, and estuary areas) during my self-protected time. I collected, recorded, and occasionally analysed the retrospective reflexive data at these locations. Some mapping was completed indoors to offer room and space; however, a short period of mindfulness was always practiced before and after data collection, data recording, and data analysis. I certainly found that green and blue open spaces allowed me the ability to mentally recollect and record difficult and challenging events more comfortably, and safer than when I initially tried to do so in office or home environments. Nutsford, et al (2016) noted that even the sight of a blue space, especially the sea, can be soothing. These effects are added to by the aesthetic appeal of water (sound, colour, motion and context) as there can then be a sensual connection allowing the opening of one's mind (Völker & Kistemann, 2011) much like green spaces, which allow a reflective space which can be mood-enhancing (Aspinall, Mavros, Coyne, & Roe, 2013).

### **5.2.1 Data Collection**

Each section of my data collection, analysis, and mapping narrative section includes a Table taken from my source Table (Table 8) which displays my “tactics of rhizoanalysis” (MacNaughton, 2005 p.119) which I have adopted and modified from MacNaughton, (2005 p.123 & 131). MacNaughton (2003; 2005) was herself influenced by Deleuze and Guattari, (1987); Davies, (2001) and Alverman, (2001). My data

collection, analysis, and mapping Table (Table.8) also utilises method from Leafgren’s (2016 p.96) rhizomatic analysis study, as well as acknowledging Honan and Sellers’ (2006) three rhizomatic connections. Finally, I sought guidance from Chang’s “10 strategies of analysis and interpretation” (2008 p.131) to ensure autoethnographic data guidance and authenticity to maintain a layered data management process.

Table 8 *Tactics of Rhizoanalysis*

<p><b><u>Generate Text – Data Collection</u></b></p> <ol style="list-style-type: none"> <li>1. Collect Diverse Data</li> <li>2. Generate / locate text of moments where my/others behaviours have challenged.</li> <li>3. Data to be collected through - Journal data, Retrospective &amp; Reflexive, Policy / Evidence Base.</li> <li>4. Remain nomadic in data collection = <i>A layered text.</i></li> </ol> <p><b><u>Analyse Text</u></b></p> <ol style="list-style-type: none"> <li>1. Interrogate Text – Read, Reflect, Re Read, Reflect...(Repetition)</li> <li>2. What is happening in the text?</li> <li>3. Is my voice in the text?</li> <li>4. Are the voices of others in my text?</li> <li>5. Are there missing voices in my text?</li> <li>6. Does my text reflect the subject (Behavioural Challenge, Inter/Subjectivity, Dementia)</li> <li>7. Is my text congruent?</li> <li>8. Are there exceptional experiences in my text?</li> <li>9. Is difference and similarity reflected in my text? = <i>A layered understanding.</i></li> </ol> <p><b><u>Understanding – Using Diverse Fragments</u></b></p> <ol style="list-style-type: none"> <li>1. Map &amp; remap multiple views/lines –</li> <li>2. Connect data fragments to each other</li> <li>3. Connect fragments of data to the outside (Be nomadic),</li> <li>4. Connect fragments to me (Be reflexive),</li> <li>5. Connect fragments of data to others</li> <li>6. Connect fragments to a wider evidence base = <i>A layered account.</i></li> </ol>
--

The data collected for this autoethnography supports the telling of my story, however my story was always told with others in mind (Chang, 2008; Wall, 2008). My story was created through a retrospective reflexive study using a series of personal memories, reflections, and self-disclosures. All of which relate to moments associated with behaviours that have challenged me, or others; all reflected through my personal and professional life as a mental health nurse working for a mental health liaison service in a general hospital. To initiate this process of understanding of me (‘I’) in my study, and

to describe my “social self” as a point of reference I completed a data pre-collection culture-gram (Figure 9) based on a model developed by Chang (2008 p.97). The rectangles represent established social categories, which are joined together by connective lines. The shaded ovals are subjective categories represented as my initial self-identifiers. Finally, the shaded centre circle represents my three primary self-identifiers (Professional -Nurse, Loving & Diverse). All of which I hope will be captured and represented in my study. My culture-gram has captured a point in time, but this moment is not fixed, it is transient and changeable, much like my becoming self/other. This is described by Deleuze & Guattari (1987 p.275) as, “the self is only a threshold, a door, a becoming between two multiplicities”.

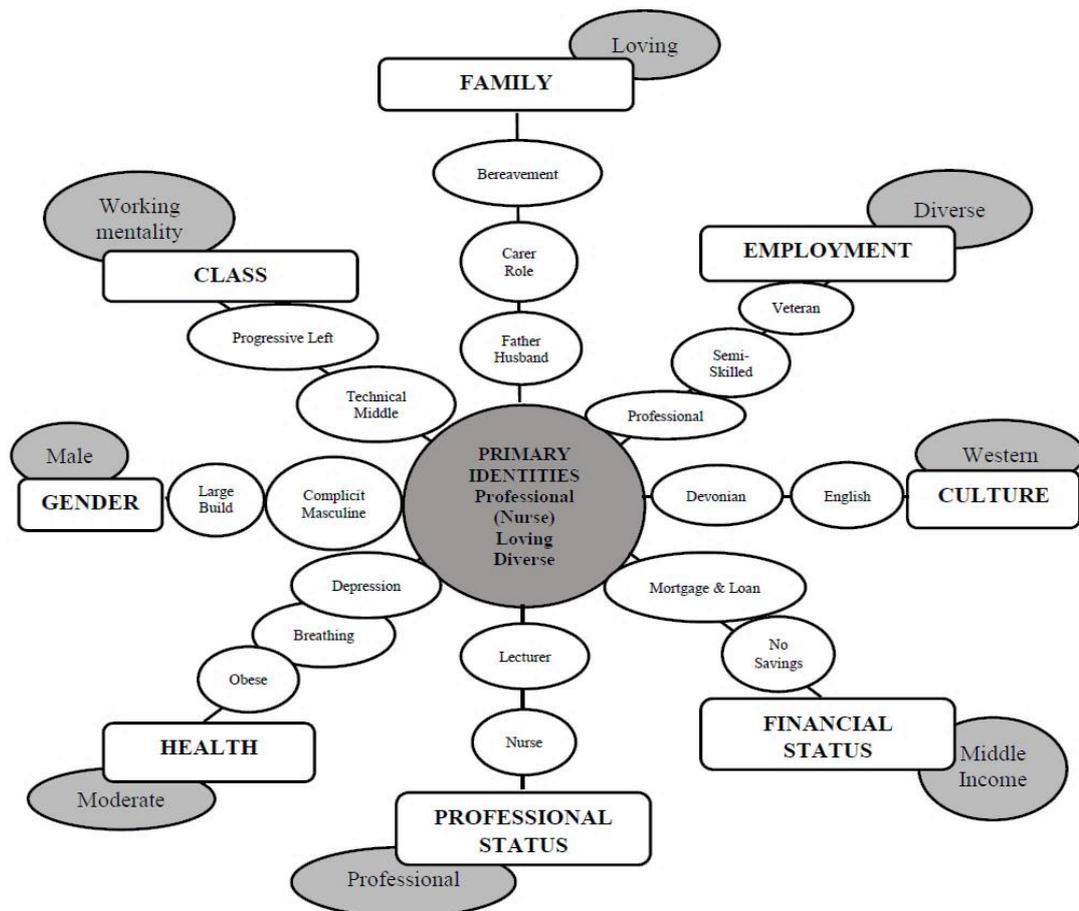


Figure 9 Culture-Gram (Chang, 2008)

### **5.2.2 *Retrospective Reflexivity***

The data collected in my study is collected through a process of retrospective reflexivity. Retrospective reflexivity is a form of rumination which is only possible through contemplation over a passage of time and considered through a series of sequential experiences (Drozdewski, 2015). I considered this and chose to concentrate professionally on a four-year passage of time. However, in order to honour my chosen autoethnographic methodology and a Deleuzian theory of time (Deleuze, 1994; Voss, 2013) I have also reflected and collected data of non-nursing personal memories, which are extended across my life cycle.

This method of reflection allowed me to draw on my historic memories of behaviours that challenge, but not get lost in the past by creating a critical reflection of a human experience through a prism of the present (Nowakowski, 2016). It was important to me that I did not influence my study, but that the study influenced me (Attia and Edge, 2017). I was however mindful that the process of retrospective reflexivity could influence the research process by the allowing my subjective experience/s to set the agenda of the research (Hesse-Biber, 2007; Palaganas, Sanchez, Molintas, & Caricativo, 2017). Knowing this, I wanted to reduce the potential of subjective bias influencing the study's agenda. Hence, I needed to be transparent and open, signposting the reader to my subjective place/position in the study. It therefore remained very important to be retrospectively reflexive throughout the study as the data needed to "shed light" on how my history may have influenced, or impacted on others (Valandra, 2012 p.218). This potential of inter/subjective experiential influence was a central factor of my study, so rather than being ignored it needed to be nourished and highlighted when present. This

required my study's narrative to be congruent, trustworthy, and transparent (Polit & Beck, 2010).

Many of the retrospective events recalled included interactions with others which have influenced my thoughts, feelings and actions (subjectivity) and have at times guided my nursing practice and potentially my decision making (Ellis et al., 2011; Pitard, 2016). On occasions, these event memories have related to family, friends, professionals, practitioners, and even policy makers. However, in most cases, they have been people experiencing dementia, and facing the confusion and distress it can bring in hospital ward environments; these are the people who have been truly influential and inspirational in my story (McKeown, Clarke, Ingleton, Ryan, & Repper, 2010).

### **5.2.3 *Autoethnographic Data***

Autoethnographic data collection involves the systematic collection of personal data through a process of self-inquiry in order to make sense of a particular cultural experience (Ellis, 2010; Ellis et al., 2011). Although the data collected required an understanding of self my study was not just a descriptive self-memoir, or as Ngunjiri, Hernandez & Chang (2010 p.2) describe "self in a vacuum". There is a belief held by some that autoethnography data is a somehow a self-obsessed narrative (Campbell, 2017; Ellis & Bochner, 2000; Trahar, 2013). Labeled by some as, "unethical" and "intellectually lazy" (Delamont, 2007 p.2-3) and focusing on the "wrong side of the power divide" (Delamont, 2007. p.2-3). However, this has not my experience or understanding of the methodology. I would even counter-argue that non-reflexive narrative research methods often exploit "research power" through a series of "invasive" and "self-serving" interviews, using others' narratives to speak on behalf of

the researcher, and indeed the whole culture (Adams, Holman, & Ellis, 2015. p.12). This sentiment is echoed by Karnieli-Miller, Strier and Pessach (2008 p.281) who highlight the risk of a power dynamic emerging in qualitative research paradigms, stressing that, “participants are not always considered to be the real experts”. I feel that my perspective of autoethnography was captured succinctly by Stahlke Wall (2016 p.8) as, “the power of one to explore and critically analyse the complexity of social events or topics for the purpose of transformation and social justice”.

#### **5.2.4 *Rhizomatic Data***

Once data was collected it was mapped as a method of making sense. Data mind mapping can come in many forms (MacDonald, 2016). In the case of my study I utilised a rhizomatic analysis mapping process (Deleuze & Guattari, 1987; MacNaughton, 2005). I chose to use this rhizomatic mapping process as it promoted freedom of thought and knowledge creation (Deleuze & Guattari, 1987; Styhre, 2001). This form of analysis also recognised and represented the complexity of the biopsychosocial factors of human nature/dementia during moments of behavioural challenge (Fox, 2014), and how these factors could have influenced intersubjectivity and decision making. These were central aims of the study.

Rhizomatic mapping (Deleuze & Guattari, 1987) led to data being collected, analysed, and at times mapped as one process, much like Framework Analysis (Ritchie & Spencer, 1994). However, unlike Framework Analysis and other linear and fixed formats of data, rhizomatic mapping creates a flux and flow between data collection, analysis, management and the mapping of data. It is also not seeking to interpret an integral meaning (Dashper, 2016). Therefore, using this method of mapping enabled a

series of “becomings” to emerge, including the mapping of “realms that are yet to come” (Deleuze & Guattari, 1987 p.6; Grellier, 2013). Masny and Waterhouse (2011 p.293) stress that when making sense of data it is “not what data is, but rather how it might become”. Rhizomatic mapping is a journey and not a destination; an open-ended logic that materialises as a series of “and... and ... and...” which unifies to carry “enough force to shake and uproot the verb to be” (Deleuze and Guattari, 1987, p.27).

### ***5.2.5 Reflexive Study Journal***

Any data collected was recorded in an electronic reflexive journal in the form of vignettes, images, poems, lyrics, words, timelines, and found policy/guideline documentation. I also included my meta-ethnography findings (Chang, 2008). Data was created and inspired by recalling life cycle events in which I, or others, were challenged by personal or professional behavioural moments. Recollection and reflection of these moments subsequently produced narrative and vignette data. These narratives and vignettes often arose from producing behavioural event timelines, channeling visual and auditory memory (stimulated by images and music/lyrics), alongside the production of preliminary vignette title and story mind maps (Chang, 2008; Minge & Zimmerman, 2013; Pitard, 2016).

Reflexive journaling has been found not only to be a useful research tool but also acts to as a form of self-evaluation, as well as making connections between theory and practice (Barry & O'Callaghan, 2008; Nadin & Cassell, 2006). Alongside all of these benefits, reflexive journaling as a process not only aids the collecting of data but can also supports the coding of data (Malacrida, 2007). A small example of the data collected in my reflexive journal is shown in Figure 10 below.

**28.2.18 Boomtown Rats – first ever single that I bought aged 12 in 1980. (15 mins) 24**

The purple and the pinstripe Mutely shake their heads  
A silence shrieking volumes  
A violence worse than the condemn  
Stab you in the back yeah  
Laughing in your face  
Glad to see the place again  
It's a pity nothing's changed

**25.3.18 (60 mins) 27**

Challenging Events Timeline

Childhood challenging behaviour memories - 1-18

Childhood bullying - 5-16

Challenging relationship/s - 20-32

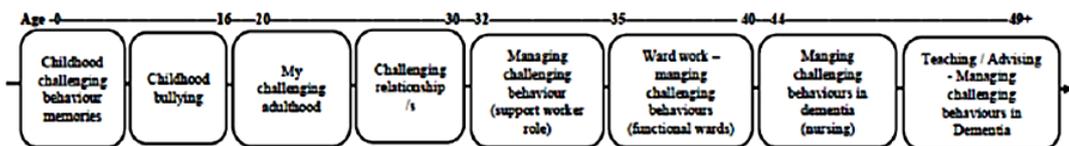
My challenging adulthood - 17-32

Managing challenging behaviour (support worker role) - 32 - 35

Ward work – managing challenging behaviours (functional wards) - 35 - 40

Managing challenging behaviours in dementia (nursing) - 44 -49+

Teaching managing challenging behaviours - 46 - 49+



**11.4.18 – (75 mins) 33**

**Incidents and Events to consider as vignettes – ‘Experiential Self’ & ‘Adapted Self’**

I get knocked down, but I get up again

Loss and my Boss

The judge jury and the executioner

French connection

Mummy’s boy

Madness through sadness

When hatred becomes habit

Whistle down the wind

Hero

Merry Christmas

Sedating through hating

I just want to feel real love

The fishpond

Target practice

The Cobra

You do love me don’t you?

***The fishpond 30.5.18 (45 mins) 46***

*She was discharged that day and shortly after found hanged under her stairs. I don’t know why she hanged herself, I imagine having no role to return to didn’t help? However, had I not allowed myself to be directed away from talking to her that day, perhaps I might know more. And, at least been able to satisfy myself that I had done all I could. However, I didn’t, and I will always be saddened by that decision, however much it guided my future practice. My role means that I will see sadness, distress, despair and death, but I always want to feel I did all I could.*

Figure 10 Example of Reflexive Journal Data.

## 5.2.6 Data Log

All data collected was documented on a spreadsheet which acted as a ‘data log’ (Chang, 2008) (Figure 11). The data log served multiple purposes, these included: identifying data sets, producing numbered data labels, finding data associated with self and/or others, recording data collection timescales and perhaps most importantly, it offered an informal and accessible data search tool to aid further analysis (Chang, 2008; Richards, 2015). Data was recorded on the data log in the form of a labelling spreadsheet (Figure 11). Data was recorded on the spreadsheet at the same time as collection and entry into the reflexive journal (Figure 10). The log allowed further retrospective examination when data gaps emerged, as well as encouraging sense making to surface, and the discovery of connections between self and others (Chang, 2008; Srivastava & Hopwood, 2009). All data recorded in the reflexive journal and data log were given a data identification (ID) numbers under Data set. These ID numbers were used to aid the rhizomatic analysis mapping process (Figure 13 p.83).

Data Set	Journal Page	Date Collected	Data Type	Collection Location	Timeframe	People Involved	Source	Place of Event	Time Coll
1	1	1.9.17	mind map	H		Self	Self		
2	2	12.2.18	picture	H	1971	self/family	Self/Other	Home	
3	3	12.2.18	vignette	H	1975	self/teacher	Self	School	
8	5	13.2.18	vignette	M	1983	self/teacher	Self	School	
11	6	13.2.18	poem	M	1992	self/mum	Self	Home	
21	12	28.2.18	timeline	H		self	Self		
22	12	28.2.18	picture	H		self/family	Other	Home	
23	13	28.2.18	lyrics	C		self	Self/Other		
24	14	28.2.18	lyrics	H	1980	self	Self		
25	15	12.3.18	vignette	M	2018	self/patient	Self	Nursing	
26	17	20.3.18	vignette	M	1978	self	Self	School	
37	38	26.4.18	vignette	S	1987	self/others	Self	Home/Navy	
38	40	19.5.18	picture	H		self/others	Other	Nursing	
39	41	20.5.18	mind map	H		self	Self/Other		
40	41	20.5.18	vignette	H	2001	self/others	Self	Home	
43	44	27.5.18	vignette	S	2001	self/others	Self	LD	
44	44	27.5.18	vignette	S	2002	self/others	Self	LD	
45	45	27.5.18	vignette	S	2005	self/others	Self	Nursing	
46	46	30.5.18	vignette	M	2006	self/others	Self	Nursing	
47	46	30.5.18	vignette	M	2017	self/others	Self	Nursing	
48	47	9.6.18	Other narrative	S		self/family	Self/Other	Home/school	
49	47	9.6.18	vignette titles	H		self/others	Self	Nursing	
50	48	9.6.18	picture	H		self	Self		
67	61	10.10.18	literature	H		others	self		

Figure 11 Example of Data Log

### **5.2.7 Reflection on data collection**

Vignettes and narrative data were produced through retrospective reflexivity guided by timelines, mind maps, and other data sets such as images, poems, song lyrics and words which spontaneously arose from moment to moment. The data collected emerged during self-guided retrospection, however, at other times it arose out of the ether, emerging by the triggering of moments from personal memory and “emotional recall” (Douglas & Carless, 2013; Ellis, 1999 p.671). This can be somewhat of an unpredictable approach, which can also lead to distressing and traumatic memories arising (Gariglio, 2018). This required me as a qualitative researcher to maintain a balance between sharing my emotional experiences and maintaining my emotional wellbeing (Jackson, Backett-Milburn, & Newall, 2013). However, not only can recalling these emotional experiences be negative and distressing, it can also become a cathartic experience (Dickson-Swift, James, Kippen & Liamputtong, 2009; Tuval-Mashiach et al., 2004). Especially if the story is self-evaluated accurately, given meaning, and re-organised to produce a coherent explanation of the event (Tuval-Mashiach et al., 2004). Re-storying of traumatic events can create new meaning by *readdressing* blame, and improving self-esteem (Uy & Okubo, 2018).

## **5.3 Data Analysis**

### **5.3.1 Introduction**

The data I had collected through retrospective reflexivity was diverse and multimedia and included text, images, music lyrics and poetry. It therefore needed a process of analysis that would accommodate multimedia memories. I noted that some authors suggested content analysis as a multimedia data analysis method that addressed multimedia data (Dimitrova, 2003; Hanjalic, Sebe, & Chang, 2006; Neiger, Meyers &

Zandberg, 2011). However, this method of analysis did not sit well within my ontological and epistemological or frame of reference. Whereas, Rhizoanalysis supported the analysis of multi-type data, and I felt was congruent within my study. Table 9 below is a reminder of my tactics of rhizoanalysis data analysis plan, and is taken from Table 8, as is Table 10 which represents my data mapping process.

Table 9 *Data Rhizoanalysis Plan*

Analyse Text (Data)
1. Interrogate Text – Read, Reflect, Re Read, Reflect...(Repetition)
2. What is happening in the text?
3. Is my voice in the text?
4. Are the voices of others in my text?
5. Are there missing voices in my text?
6. Does my text reflect the subject? (Behavioural Challenge, Inter/Subjectivity, and Dementia)
7. Is my text congruent?
8. Are there exceptional experiences in my text?
9. Is difference and similarity reflected in my text? = A layered understanding

The first stage of analysis of my rhizoanalysis was to interrogate the text. I did this by reading, re-reading, and reflecting on the journal data. This process was not only completed at the point of data saturation, but also throughout the data collection stage. In doing this, and by reflecting on the data throughout, my data analysis occasionally took off in unforeseen changes of direction. This is not unusual when using rhizoanalysis as a rhizome ruptures unpredictably and can disrupt preconceived concepts, offering alternative perceptions and understandings; new becomings (Deleuze & Guattari, 1987; Masny, 2013). After all, rhizoanalysis is “both process and product” (Sellers, 2015 p.6).

To interrogate the text, work out what was happening in my data, and remain rhizomatic, I commenced stage two of the data analysis (Table. 9). This required a process of rhizomatic mapping (Table. 10) necessitating freedom of thought and

knowledge creation (Deleuze & Guattari, 1987; Styhre, 2001) whilst also allowing a flux and flow between data collection, rhizoanalysis, and rhizomatic mapping, which I believe other linear or hierarchal formats would not have allowed (Dashper, 2015). These structured, and somewhat constricted forms of chronological analysis are often referred to as a root-tree system as they seek to find causality; metaphorically in the same way as the roots feed the leaves of a tree in one direction (Deleuze & Guattari, 1987; Robinson & Maguire, 2010; Sukovic, 2008).

In contrast, rhizoanalysis through rhizomatic mapping suggests there is just not one direction “any point of a rhizome can be connected to anything...this is very different from the tree or root, which plots a point and fixes an order” (Deleuze & Guattari, 1987, p.7). This freedom of thought and direction fitted well with my epistemologically and ontologically position (Deleuze & Guattari, 1987; Deleuze, 1994; Rae, 2014). It was important to me as the researcher that my autoethnography was an iterative process that permitted the application of flexibility as a form of self-inquiry; much like my retrospective experiences (data) which were also not linear or predicTable (Belbase, Luitel, & Taylor, 2013).

### 5.3.2 *Data Mapping Process*

Table 10 *Rhizomatic mapping process*

Rhizomatic Mapping
1. Mapping & remapping multiple views/lines
2. Connect data fragments to each other
3. Connect fragments of data to the outside (Be nomadic)
4. Connect fragments to me (Be reflexive)
5. Connect fragments of data to others
6. Connect fragments to a wider evidence base = A layered account

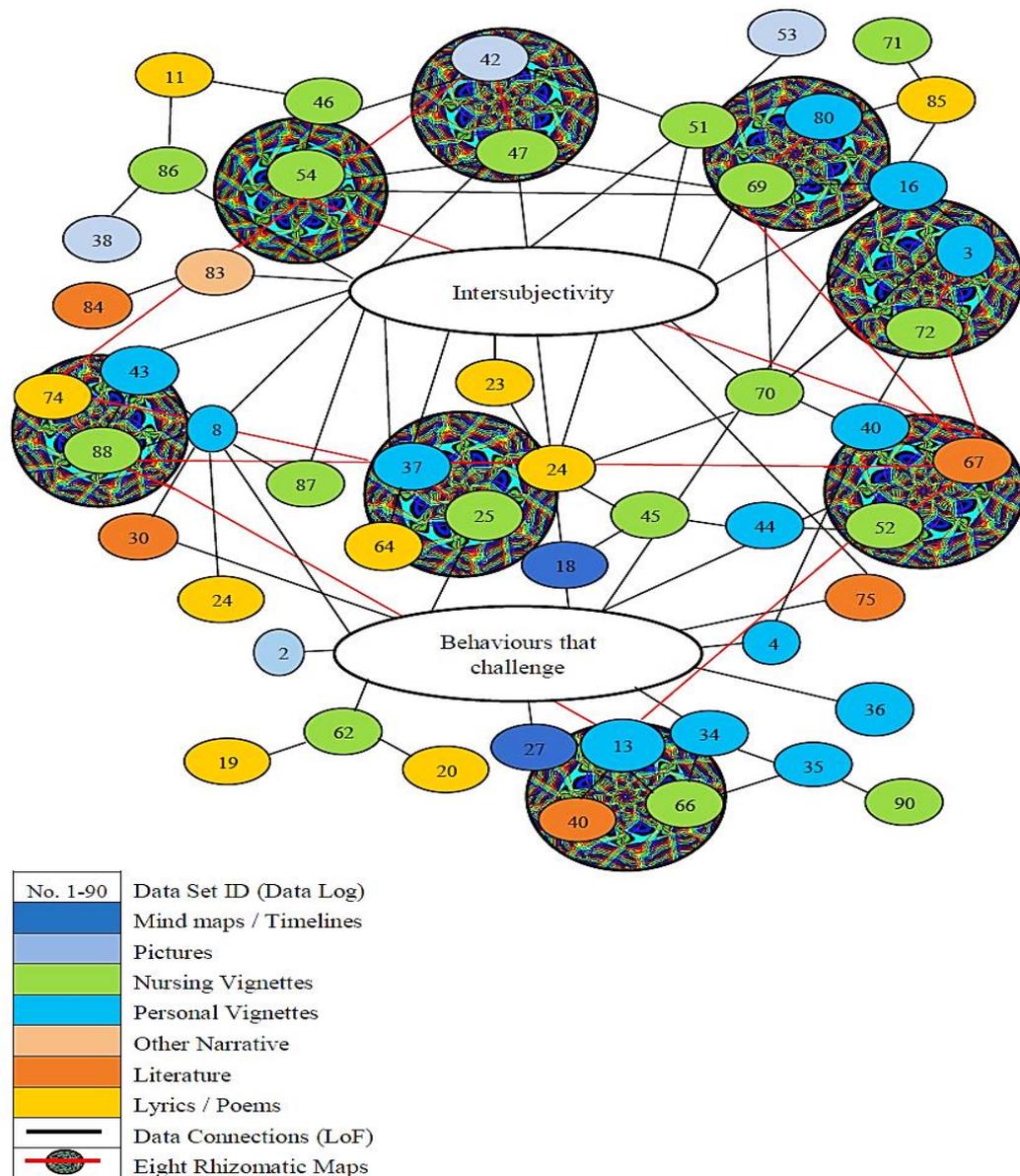
I began to analyse my data by initially mind mapping and remapping journal data to my meta-ethnography findings and then to my emerging reflexive journal data. I completed this initial analysis aligned with my stage one and two of my rhizoanalysis plan (Table.9). This required a series of readings and re-readings of my meta-ethnographic findings and my journal data. In doing so, I made preliminary connections between data sets and data types. However, I accepted that some of these initial connections would change due to the rupturing of those connections, and in doing so would allow new heterogenic connections to emerge through a new “lines of flight” (Deleuze & Guattari, 1987 p.3). Deleuze and Guattari, (1987 p.3) refer to these lines of flight (LOF) as a bridge to a new becoming (Usher, 2010). It is the “already happened but still there, open, somewhere between ‘right now’ and the closest future” (Fournier, 2014 p.122). At this stage it was only the connections between my meta-ethnography central findings (intersubjectivity and behaviours that challenge) and my early readings of fragments of my journal data that were made, and then re-made.

Stage three, four, and five (Table 9) of my rhizoanalysis plan led to the production of several hand drawn scribbled rhizomatic and word document maps (Figure. 12), all of which were created from continued reading and rereading, and reflecting on my reflexive journal data, alongside referring to my data log (Figure. 11).



with the data led to three further journal vignettes being included into my rhizomatic mapping process (Figure 13). Once this step was completed data was then saturated, and this allowed the final process of analysis to be completed. Data saturation can mean different things to different researchers, in my case it referred to no new data emerging. However, I reminded myself that my priority was to produce a depth of data, and not just be directed by the quantity of data (Fusch & Ness, 2015).

This final process of my rhizoanalysis involved a further repetition of stages one and two of my rhizoanalysis plan, but also moved onto stages six to nine (Table.9). This final reading / re-reading of my entire journal data was about making sense of intersubjectivity in behaviours that challenge in dementia by allowing the nomadic connection and disconnection (Table.10) of lines of flight to be made (Deleuze & Guattari, 1987). This was completed by mapping multiple diverse fragments associated with me, others, and the outside evidence base (Figure.13). In doing so I recognised that my methodology and analytical approach meant that “my sense (making) was not about interpretation” (Cole & Masny, 2012 p.82) but instead it offered an “assemblage” (Deleuze & Guattari, 1987 p.3), a non-static personal rhizomatic “image of the world” (Deleuze & Guattari, 1987, p. 12). Once this assemblage (Figure 13) was found it bestowed my study with a “plane of consistency” (Deleuze & Guattari, 1984 p.507). A plane of consistency is a space where the diverse and the heterogeneous can meet to allow nomadic movement which can assemble (Deleuze & Guattari, 1984) to offer a layered account (Table. 10 & Figure. 13).



*Figure 13* Sense Making Maps

The process of rhizomatic mapping (Table. 10), shown as my assemblage in Figure 13 generated eight interconnected sense making maps that represent my nomadic narrative, and are also a platform for developing my concept of ‘becoming intersubjective during moments of behaviours that challenge’. The eight sense making maps are described in context in my ‘**Sense Making Maps**’ section. Figure 13 is coloured and numbered for visual purposes, and to represent how data types are connected during the process of mapping. The rhizoanalytical mapped assemblage displays data connections through

black lines, and the connections between the eight sense making maps (coloured as kaleidoscope images) are represented by red lines (lines of flight). The numbers displayed are identifying (ID) label numbers taken from my data log spreadsheet (Figure 11) and the disc colours represent data type. These are all shown in the key in Figure 13.

However, it must be reiterated that these lines and writings do not signify a singular truth; “writing has nothing to do with signifying (meaning)...it has to do with surveying, mapping, even realms that are yet to come” (Deleuze & Guattari, 1987 p.5). Once a concept moves from virtual to actual, it is on a plane of becoming; it is an ongoing never-ending process of discovery created by memories and experiences (Ansell-Pearson, 2005); a map of multiplicity (Deleuze & Guattari, 1987; Masny, 2013).

## **5.4 Key ethical issues**

### **5.4.1 Introduction**

My study has retrospectively explored my personal and professional (nursing) memories, experiences, and understanding of behaviours that challenge. I have also considered how this self-exploration connected to a cultural nursing narrative of the subject and whether these personal and professional narratives influenced my intersubjectivity and treatment/support decision-making when caring for people living with dementia.

I tell my story through narratives and vignettes and this has required me to recognise that my stories may implicitly, or explicitly, implicate others (Ellis et al., 2011). Nevertheless, I do acknowledge that I have control over how the stories are written, and

the modality or tone of the writing (Lapadat, 2017). I was mindful that I must not relinquish my responsibility to others who may be an intimate part of my story (Ellis, 2007) by understanding that “storytelling requires a commitment to speak the truth” (Frank, 2016 p.21). To do this I have addressed relational ethics and all other ethical requirements of an autoethnography study by utilising guidelines developed by Sikes (2015) Table 11. Table. 11 displays how these requirements (if relevant) have been met within my study.

I have adapted these (Sikes, 2015) guidelines slightly by removing one point that suggested process consent of participants, and also amended two other guidelines points where the word participants has been changed to others. I have done so as others may be indicated by my story, however they will not be active participants and my study needs a “different kind of ethics” (Ferdinand, Pearson, Rowe, & Worthington, 2007 p.1).

Table 11 *Adapted Autoethnography Ethical Guidelines based on Sikes (2015)*

<b>Autoethnography Ethical Guidelines</b>	<b>My Study Examples</b>
Protect people whose lives are the focus and substance of my research;	All vignettes used pseudonyms and/or composite characters and any people or places described were also anonymised - <b>Confidentiality, Anonymity &amp; Consent</b>
Respectfully depict those people;	Respect of/towards others is central theme of the thesis construction/methodology.
Be alert to the potential misuse of interpretational and authorial power;	Data collection, analysis and making sense - Internalised authenticity considered and voices of others are in my text <b>(Table 8)</b> .
Be aware of tricky and slippery questions and issues around truth/s (or ‘truth/s’) (Medford, 2006 p.853);	What is truth is discussed widely – A crystallisation of many truths was sought rather than one – <b>recapping mapping</b>

Avoid ‘violent’ textual practices which shape and tame the lives that we use as ‘data’ in order to present and privilege a version that serves my purpose (Bergin & Westwood, 2003; Redwood 2008);	The balance of vignettes and data collected, analysed and presented offers text which is diverse, rich and non-self-serving ( <b>Table 8</b> ) - <b>Confidentiality, Anonymity &amp; Consent</b>
Respect others’ autonomy and the voluntary nature of their contribution and document the informed consent processes that are foundational to qualitative inquiry (Congress of Qualitative Inquiry, 2007);	Prepared for, but not required – Data is drawn from personal memories of events, experience, emotions and self-inquiry
Recognise the conflict of interest or coercive influence when seeking informed consent after writing the manuscript (Jago, 2002; Rambo, 2007);	Prepared for, but not required - Data is drawn from personal memories of events and self-inquiry
Consult with others, such as my institutional ethics committee (Chang, 2008; Congress of Qualitative Inquiry, 2007);	Institutional ethical approval sought and gained before data was collected – <b>Appendix 2</b>
Do not publish anything that I would not show the persons mentioned in the text (Medford, 2006);	The risk of ‘othering’ is acknowledged and considered - <b>Confidentiality, Anonymity &amp; Consent</b>
Beware of internal confidentiality: the relational risk is not that the researcher will expose confidences to outsiders, but that confidences will be exposed to others or members of their family, friendship or acquaintanceship networks (Tolich, 2004; 2010);	The readership of the completed thesis was considered. Confidences were protected through anonymity and non-naming including my relationship/friendship to others - <b>Confidentiality, Anonymity &amp; Consent &amp; Responsibility to self and others</b>
Treat my autoethnography as a permanent ‘inked tattoo’ and attempt to anticipate my own, and others’, future vulnerabilities;	I was very mindful of the longevity of data and vignettes shared – these were addressed through clinical supervision - <b>Responsibility to self and others</b>
Understand no story should harm others, and if harm is unavoidable, take steps to minimize that harm;	As above - <b>Responsibility to self and others</b>
Minimize risk to self or others, my default position should be that you should use a nom de plume (Morse, 2002);	As above - <b>Responsibility to self and others</b>
Assume that all people mentioned in the text will read it one day (Ellis, 1995).	As above - <b>Responsibility to self and others</b>

#### 5.4.2 Confidentiality, Anonymity & Consent

My personal narrative has inferred others, these have been colleagues, peers, friends, acquaintances and family. Some of these people will still part of my current story, but many are deceased. Whilst collecting and writing my data I have referred to the ethical

guidelines that I have worked within (Sikes, 2015). I acknowledge that presenting others in my story that are deceased has added additional ethical questions, as although my narrative could act as a memorial, it also does not allow the person to question my memory of events or indeed them as a person (Ellis, 2007). The process of implicating others and the subsequent ethical considerations in autoethnography is known to as “othering” which is unavoidable, but must be acknowledged (Andrew & Le Rossignol, 2017 p.228; Roth, 2009).

I have therefore approached my writing with sensitivity and offered “narrative integrity” throughout (Brockmeier & Carbaugh, 2001 p.76). I have done so by carefully balancing the production of an open and honest account, with the risk of taming the narratives in order to present version that serves my purposes and is guarded (Bergin & Westwood 2003; Redwood, 2008). I needed to discuss difficult subjects openly in order to offer autoethnographic congruence (Allen-Collinson & Hockey, 2008). Although the study has implicated others it does not mean it was unethical or wrong, as long as I wrote respectfully, and I did all I could to protect others (Manning & Adams, 2015).

To protect anonymity all vignettes I used had pseudonyms and any people, professionals, and/or places described were also anonymised to maintain confidentiality. Where vignettes included a person living with dementia pseudonyms and composite characters were created to protect that person from identification (Ellis, 2004). With regard consent, this can be somewhat a difficult in autoethnography (Wall, 2008); I am the researcher, the researched, and I am the participant (Doloriert and Sambrook, 2009). The data is my memories, thoughts, senses, emotions and

experiences. However, I very clearly thought about the implications of such a journey, and with an open mind I was very willing to take that journey and see where it took me.

#### ***5.4.3 Responsibility to self and others***

There is no expectation or evidence that anyone referred to in my study was harmed by any content in the thesis, as all data used was carefully considered through ethical guidelines developed by Sikes (2015). However, I found the process of reflecting on my personal concept and perception of behaviours that challenge through childhood, into my adulthood, and now in my practice as a mental health professional difficult at times. To protect my emotional wellbeing, I utilised regular academic supervision. I also requested and attended additional nursing clinical supervision from my line manager to support my emotional wellbeing, mindful she was a trauma expert and therapist. I also used basic personalised mindfulness techniques before and after the data collection to ground myself and close the sessions safely (Pensoneau-Conway et al., 2017 p.24; Vermersch, 2009). Ultimately, I found that the process of writing about my experiences of behaviours that challenge a cathartic process which has produced a new chapter in my life; a new becoming (Deleuze & Guattari, 1987; Richardson, 2001).

#### ***5.4.4 Data Management and Storage***

The majority of journal data was written into an electronic journal, for the purpose of aiding analysis. Any hand-written data collected (maps/notes) were locked in a filing cabinet which only I had access to. Electronic data was held on an encrypted document file within a personalised drive, on a password protected either PC / laptop. If data was transferred between PC and laptop it was done so on an encrypted flash drive. Data documents in the form of Microsoft word, PDF, Excel and other electronic formats will

be held on a secure storage at Lancaster University for 10 years. All paper ‘back up’ copies will be destroyed when the PhD is awarded, or the study is deemed complete by the viva panel, in line with Lancaster University’s Research Data Policy (2015). Quality and integrity standards were met in line with Lancaster University’s Research Ethics and Research Governance: a code of practice (2009).

## **6 Chapter 6 – Findings & Discussion**

### **6.1 Introduction to chapter**

My findings and discussion chapter are presented initially through eight sense making maps which are then discussed (mapped) point by point. These maps are the conclusion of my analysis and represent a layered autoethnographic account and assemblage. My sense making maps make connections between evocative narrative data, other found multimedia data, and the wider evidence base in order to offer a balanced account of my story of becoming intersubjective in the midst of behaviours that challenge in dementia.

As discussed, my analysis took the form of rhizomatic mapping, which I acknowledge is not linear as it “has no beginning or end, it is always in the middle” (Deleuze & Guattari, 1987 p.25). However, when I reached data saturation, and completed my data analysis process, my narrative fell into a story type structure, formed as a beginning, middle and end. This was not deliberate and conscious decision, but only something I noted once I had analysed and made sense of my data mapping to form my narrative findings. But even Deleuze and Guattari acknowledge that “we require just a little order to protect us from chaos” (Deleuze & Guattari 1994: p. 201; Williams, 2011).

My eight maps and narrative points therefore represent a timeframe which delineates a sequential, but transient time, where I (experiential and adapted/nurse) became aware of my place in the midst of behaviours that challenge in dementia. Once my story was told it was recapped through further re-mapping which is conceptualised to highlight what I had found to be sitting behind my told story. Finally, the findings are developed into a (self-practice) model of nursing in the midst of behaviours that challenge in

dementia. I hope to have written my findings and discussion section in a way that is not self-indulgent, as my aim is to offer a layered account that not only recognises the importance of self but also the need to acknowledge the position of otherness within intersubjectivity. I acknowledge at times that my study is reflexively emotional, but it is also grounded in the narrative of other/s, layered amongst a range of relevant and associated studies.

## **6.2 From rhizomatic mapping to data findings**

My study methodology (Autoethnography) and data analysis (Rhizoanalysis through Rhizomatic mapping) has allowed for an open-ended, creative, and morphing exploration of data which have formed an emerging, yet temporary understanding and assemblage of behaviours that challenge in dementia (Strom & Martin, 2013). These emergent ideas have opened the opportunity for me (and the reader) to connect and disconnect with personal and professional forces that have influenced my understanding of behaviours that challenge. These include social and personal disruptions to my own emotional resources and wellbeing (Greer, 2016). These temporary understandings collided, dispersed, and at times combined into an autoethnographic and rhizomatic assemblage of my becoming intersubjective *in medias res* of behaviours that challenge in dementia.

## **6.3 Findings...Sense Making Maps**

The aims of my study were to make sense of my (first-person) experiences of intersubjectivity in the midst of behaviours that challenge in dementia, understand whether these experiences influenced my decision making, and how 'I' as a nurse could manage this intersubjectivity to achieve a positive outcome. These aims were

guided by my meta-ethnographic literature review, which concluded with a conceptual model that places the balance and outcome of intersubjectivity in dementia in a gap that sits between the gateways and barriers of positive intersubjectivity (Figure 3). This gap is where the 'I' and 'Thou' (Buber, 1970) meet during these behaviours that challenge intersubjective moments; the gap I call the *in medias res* (in the midst of things). If we start our story in the midst (middle) as suggested by Deleuze and Guattari (1987) and Yountae, (2014) we acknowledge that we are both drawing on the pure past, during our intersubjective living present moments, and therefore we are always in the midst of our story. I was however mindful that although each of these moments will be new "sense-events" or "becoming future" moments (Masny, 2015 p.8) they will always be transient and changing, just like the image created by the kaleidoscope as it turns.

To make sense of the gap I completed a retrospective reflexive journal which when analysed linked my pure past (life events) to my living present (role as mental health nurse) to create a transient becoming future synthesis (Deleuze, 1994; Voss, 2013) presented as eight sense making maps (Figure. 14). The vignettes and other narrative data presented in the eight sense making maps link moments of behaviours that challenge during my time working as a mental health nurse in a psychiatric liaison team to my pure past experiences of challenging life moments; to become a single assembled event. The meeting and narrative description of these experiences becomes a co-presentation of the past and the future; all of which are represented as a living present to the reader (Deleuze, 1994).

In the section below I present my narrative findings which have been identified through my rhizomatic mapping process (Table 10 & Figure 13). Each of the eight sense making

maps represents a mini chapter towards my story of intersubjectivity in the midst of behaviours that challenge in dementia. All mini chapters / maps will be presented under a mini chapter title (Figure 14). These titles were created through the interrogation of the data by repeatedly reading, reflecting, re-reading, reflecting and asking myself what is happening in the text. This was guided by stage 1 and 2 of my data rhizoanalysis plan as displayed in Table 9. To make this data visible to the reader and to link back to the data collection and analysis phases of the study the narrative chapters presented will have a numbered disc placed at the end of each data set. These coloured and numbered discs represent the data type and their place within my reflexive journal. The colours and numbers displayed on the discs can be seen/reviewed in the index of Figure 13.

The narrative findings and recollections presented in this findings section that have been taken from my reflexive journal will be displayed in italics. Any narrative (data types) associated with my role as a mental health nurse during my four years with a liaison team (vignettes) will also be marked with a single asterisk (\*). Other lifecycle experiential data (including poems, song lyrics, pictures and other vignettes) will have two asterisks (\*\*), and finally any other data types (meta-ethnography findings, other study literature, and policy/procedure) will commence with three asterisks (\*\*\*)

To offer a “layered account” (Ronai, 1995 p.395) to my autoethnography, and support my study findings, I have also referred to additional literature in relation to each of the eight narrative mini chapters. This literature is not presented in italics as it is not represented in my reflexive journal and is for narrative support and layering only. My aim is for my qualitative findings (story mini chapters) to weave together as a “golden thread” (Smith, 2015 p.91) throughout my findings. This will produce an

autoethnographic story of a nurse’s experience of behaviours that challenge, whilst making links with practice and theory to provide this layered account (Denshire, 2014; Ronai, 1995 p.395).

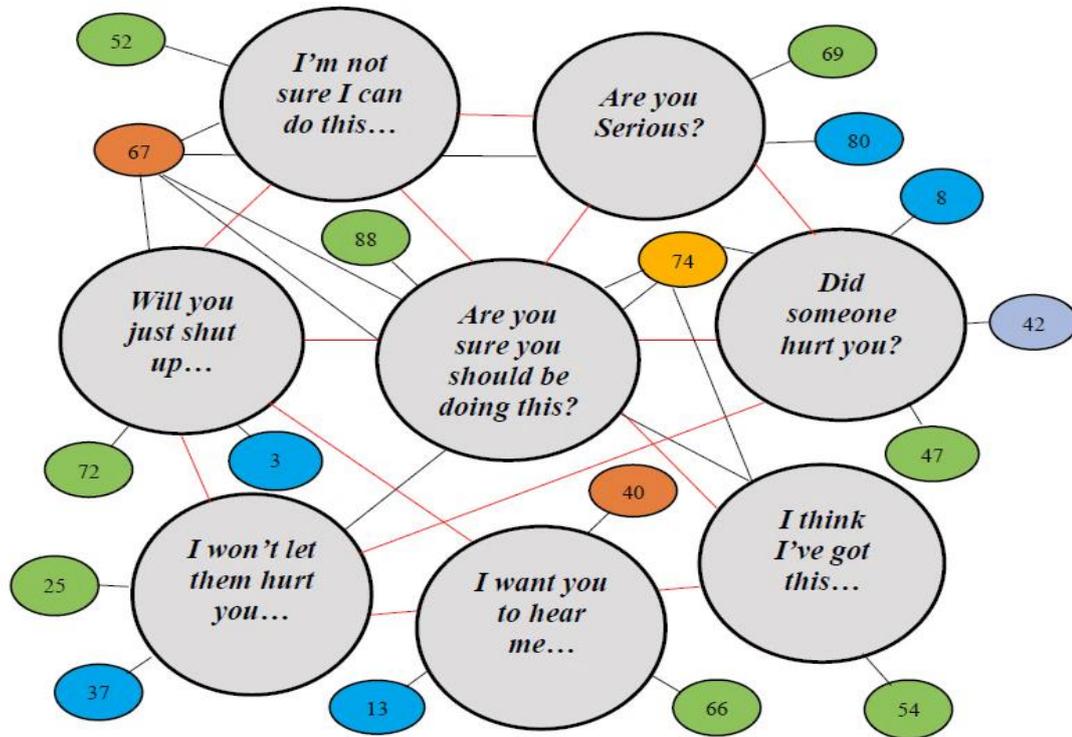


Figure 14 Eight Sense Making Maps

### 6.3.1 *I'm not sure I can do this?*

*We received a referral from a ward wanting us to assess, treat, and transfer a gentleman with dementia (Harry) who was reported to be a risk to staff and other patients. We are advised that he has served a life sentence for murdering a woman, and only recently had slaughtered a cat.*

*Ward Manager: "He is very dangerous and of course needs at least two to one, and where possible males" ... "How can anyone do that to a cat?" .... "My staff are very fearful of him and won't go near him"... "To be honest he probably needs to be sectioned and go to one of your mental health wards where he can be managed"*

*Me: "Harry won't be going anywhere until he is assessed, and even then, it needs to be appropriate, and he needs to be physically well enough to transfer".*

*I then met Harry – Harry could perhaps understand what I was saying, but his speech and cognition were so poor that responding was difficult for him and he formed very*

*few words. He had very long facial and head hair and his finger nails were long and unkempt. He certainly did not appear to be a threat to others at this stage of his life. He was in fact not particularly challenging from a care perspective, just a little reluctant to have personal care at times. He had no family and his only visitors were two female friends; his long-term cleaner and her daughter who had known him over 25 years.*

*Me: "The ward seems concerned about Harry and his risk to others"*

*Friend: "Oh" ... "he has had a difficult past" ... "He was on heroin, as was his girlfriend, back in their teens and early twenties". "Anyway... he has always been a troubled man, and had voices and things, and one day they told him to kill his girlfriend...they told him it was the best thing for her, a kind of mercy killing... so he did by smothering her with a pillow".*

*Me: So, when was this?*

*Friend: "Over 50 years ago now, he served life, and I met him shortly after he was released from prison".*

*Me: "Ok, and the cat story?"*

*Friend: "Oh that was terrible she said...he loved that cat" .... "He had a disagreement with a neighbour years ago, a nasty piece of work". "The neighbour wanted to teach him a lesson, so he killed his cat.... he never did get over it..."*

*Me: "Harry didn't hurt the cat then?"*

*Friend: "No, he wouldn't hurt a fly"*

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The appraisal of a person's actions and their influence on others is often based on cultural or social perceptions or judgements of another's actions; a value-based decision (DH, 2010). People who care for others with dementia are often advised to be guided by their conscience, however to be ethical a conscience decision needs to be informed and directed by fact, rather than a personal or shared value base alone (Alzheimer Europe, 2014, 2015). There is a moral component of nursing where judgements are made in the moment, however these judgements require self-reflective and self-awareness for the nurse (I) to effectively advocate for others (Mantzorou & Mastrogiannis, 2011).

\*\*\* *"Relational dialogue is the means by which we take account of our own and other people's values and make moral judgements about our actions" (Boyle & Warren, 2015 p.12)*

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On commencing my role as a mental health nurse in the liaison team I was unsure of whether I was ready, belonged in my new role, or indeed would be able to advocate on

behalf of others. I had faced a challenging event in my previous position as a service manager where my ability to develop my team and provide a service that met the needs of the patient group had been judged negatively, and in my opinion unfairly. This event had an extremely adverse effect on my confidence, self-esteem, and sense of self (both personal and professional).

*\*\* You took away all that I believed I was, and you tapped into my weaknesses; you constricted me and tried to fill me with your poison. You are a bully, no more, no less. You seek gratification in seeing others destroyed, and you do it in such a clever and manipulative way that you get away with it... drip...drip.... drip and then an almighty torrent of venom. All the time with a stillness, stealth, and a confidence that you will succeed in extinguishing your prey. You sank in you fangs into me and your poison entered me. You very nearly destroyed me. I began to believe that I would not survive. As your venom circulated within me, I deemed I was no longer worthy, I was a pointless, and I served no purpose.... Fortunately for me snake I am a dragon, and “When did ever a dragon die of a serpent’s poison?” (Nietzsche in Pippin & Del Caro, 2006 - P.50).*

52

Here I was, stepping back into a clinical role, and I had begun to already question my competence as a nurse, and my ability to professional make decisions. And, already I was faced with complex questions and challenges. Self-confidence and self-awareness are important factors when working in this challenging environment (NDTi, 2013). Any period of harassment or intimidation is likely to lead to a loss of self-confidence, self-esteem, and even demotivation through a sense of failure (ACAS, 2014). This in turn will develop avoidant behaviours due to a lack of self-efficacy and self-belief (Kassem, Elsayed, & Elsayed, 2015). I did not wish for this to happen, so I went on a journey of self-discovery, of which this study is a part.

Once the nurse is self-aware they need to be supported to develop self and emotional management skills, and maintain self-esteem (Foster et al., 2015; Oflaz, Meric, Yuksel

& Ozcan, 2011). The best way to do this is through clinical supervision, which should provide an element of self-caring (Horton-Deutsch, & Sherwood, 2008). This acts as a safety net for nurses who would otherwise self-neglect (Mills, Wand, & Fraser, 2015) and is especially important as some nursing environments promote a just do it and get on with it attitude (Bramley & Matiti, 2014). This approach to care often leads to a culture of guilt where nurses believe they are selfish if they self-care (Mills, Wand, & Fraser, 2015). This is unhelpful, and although self-care and self-compassion is not the answer to all of healthcare's challenges and demands, it is essential in maintaining a healthy and compassionate workforce (Barratt, 2017). To provide compassionate care nurses need to learn to be self-compassionate and recognise that protecting self is not a narcissistic act (Mills, Wand, & Fraser, 2015).

### 6.3.2 *Are you Serious?*

*\*I am in my new role as a mental health liaison nurse, when I walk onto one of the wards*

*Ward Sister: "Oh I'm glad you are here psych, one of yours has shat in my sharps box".*

*Me: "One of my what?"*

*Ward Sister: "One of your psych patients".*

*Me: (tongue in cheek) ..." And do you know which one?" .... rather taken aback that anyone with a mental health need in the hospital was "one of mine"?*

*Ward Sister: "I'm not sure" .... "I think it was her", pointing to a rather frail elderly woman, walking very slowly and holding onto a walking frame.*

*Me: "And what makes you think it is her, or as you put it, one of mine"?*

*Ward Sister: "Well it must be... no-one in their right mind would do such a disgusting thing?"*

69

A nurse's capacity to provide compassion whilst maintaining patient dignity has been described as an ethical expectation of a nurse (Bramley & Matiti, 2014); it is an essential requirement of nursing practice (DH, 2012; NMC, 2018). Person centred and compassionate care arise from the principle of empathy, which requires self-understanding in order to understand others (Barratt, 2017; Haley et al., 2017; Liberati

et al., 2015; Pai, 2015). Jack (2012) argues that nurses need to engage and understand their own emotions before they are to engage with patients in anything more than just a superficial level.

*\*\* By the time I reached secondary school the bullying and violence around me was so bad and I was so scared of everything, I would often desperately need to go to the toilet...I would try to hold on, but as the breaks came nearer, so did the beatings, and my anxiety often got the better of me.... Too frightened to ask a teacher to go to the toilet, as if I did, I was ridiculed....so it was often too late and I would have to go to the outside toilet to try and clean myself up... always secretive, always hiding...*

80

It has been argued by some nurses that staffing shortages, time pressures, and targets are restricting their ability to be compassionate (Austin et al., 2009; Josephsen, 2014; Norouzinia, Aghabarari, Shiri, Karimi, & Samami, 2015). This is alongside a nursing workforce who report the need to share their experiences and discuss the challenges they face, in order to maintain compassionate and person-centred care (Barratt, 2017; Jack, 2012). The care experienced by patients and their family and friends are often influenced by the way organisations support and treat their employees (Bramley & Matiti, 2014). Employer recognition and support is paramount in protecting nurses from “compassion fatigue” and maintain a positive culture of care (Nolte, Downing, Temane, & Hastings-Tolsma, 2017 p.4364).

*\*\*\*“If there is a culture of care that does not allow the caregiver to confirm the patient in every single care action, there may be a lack of a holistic view on the care and at the same time a lack of respect for human dignity” (Svanström, 2013 p.7).*

67

Goodman (2011) found that most studies which explored a nursing culture of care only considered a nurse’s perspective and were focused on task completion, rather than patient satisfaction. A culture of care in dementia is more than the measurement of the successful completion of a task, as care needs to be individualised, and to do this communication has to take place (Health Education England (HEE), 2018).

### 6.3.3 Are you sure you should be doing this?

*\*Another call, another referral, another ward – “a very difficult woman with dementia who is shouting...is there anything we can we do...?” I arrive the ward to meet Doris and behind the nursing station, there are two staff nurses, the senior sister, and two health care assistants...*

*Me: “I guess it is the lady over there shouting that you want me to see...”*

*Healthcare Assistant: “How did you guess” ...*

*Me: “Has she told you what she wants”?*

*Staff Nurse: “We don’t know...we haven’t asked her... can’t you just do something about the shouting”.*

*Senior Sister: “She has dementia and she wants to get out of bed...she can’t, she has had a stroke and can’t move on one side”.*

*Me: “Does she know this?”*

*Senior Sister: “I think so...but she might not remember it”.*

*I speak to Doris, who is understandably very angry...*

*Me: “Doris, you may not be aware of this, but you have had a stroke and your legs won’t hold you up at the moment”.*

*Doris: “Did I... What am I going to do?”*

*Me: “Is there anything I can help you with....is there a reason you need to get up now?”*

*Doris: “Yes.... I can’t shit laid down!”*

*Me: “Fair point”, I will speak to the ward nurses and see how they can help you”*

*Me: “Doris needs to open her bowels”*

*Healthcare Assistant: “She has a pad on”*

*Me: “I know... but I don’t know if you have ever tried it, but Doris tells me ...she can’t shit laid down”.*

*Senior sister: “Well she can’t stand up”.*

*Me: “I hear you, however, I’m sure you can find a way to make it more comforTable for her... or she continues to shout, as she needs to go to the toilet. So, can you all have a conversation on how you might help her, and I will get out of your way...”*

88

*\*\*Dementia Poem (Affleck, 2019)*

*I need the bathroom, but how do I say?*

*Nothings the same now, I don’t know the day.*

*I get so frustrated, the words jumbled when they come out.*

*Please don’t get angry if I scream and I shout.*

74

A nurse-patient therapeutic relationship in dementia requires the recognition that communication is complex, reciprocal, and unique to individuals; there is no one way to communicate with another (Jootun & McGhee, 2011). Communication “doesn’t occur in a vacuum” and practice “should should provide cues and reinforcement (as)

familiarity is helpful and minimizes anxiety” to the person living with dementia (Young, Manthorp, Howells, & Tullo, 2011 p.1082).

The ability to communicate is also central to the creation of effective team working, and the provision of caring relationship, all of which will benefit those being cared for and staff (DH, 2012). This requires the “development of emotionally competent nurse leaders who will inspire individual and organisations...and (make) positive change in society” (Horton-Deutsch & Sherwood, 2008 p.946). When communication is lacking in a nursing team the impact on patients care and treatment outcomes is negative (Norouzinia, Aghabarari, Shiri, Karimi, & Samami, 2015). Without communicating and recognising the place of other, empathic care cannot exist, and detachment will occur (Digby, Williams & Lee, 2016). This is especially relevant in dementia care where added complexities to communication may exist (Norouzinia, Aghabarari, Shiri, Karimi, & Samami, 2015).

\*\*\* *“Recognizing the patient’s own perspective is valuable.... Inadequate communication between caregiver and patient can create suffering caused by care in the form of a sense of insecurity for the patient” (Svanström, 2013 p. 2).*

67

#### **6.3.4 Will you just shut up...**

*\*As I entered the ward, I heard a loud shrieking from a side room at the other end of the ward – ‘Nurse, nurse, nurse...help me’. I turned to the nurse in charge and asked Me: Is anyone was going to respond to Mary?*

*Senior Sister: “I doubt it...anyway she has a one to one”.*

*The shouting did not stop, so I walked up to the side room and expected to see Mary’s one to one inside the room, trying to settle her down; that was not the case. Instead, her one to one, a young health care assistant was sitting outside.*

*Me: Aren’t you supposed to be with her”?*

*Healthcare Assistant: “I am, but I can’t stand it, she doesn’t stop shouting, and it gets on my nerves...can’t you give her something to shut her up?*

*Me: “No I can’t” ... I said as I entered the room, only to find another female patient climbing in bed with Mary...*

*I remove the other patient from Mary's room and guide her back to her bed space. I try to settle Mary down.... One of our nursing students spent much of remaining day with Mary, talking to her, and holding her hand at times. She was much more contented and settled that afternoon...*

72

*\*\*\*“The suffering caused by care that arose seemed to be related to caregivers' inability to be present, to show their face, and to truly encounter the patient”.* (Svanström et al., 2013)

67

Dementia can bring with it repetitive behaviours, these can include loud repetitive and incomprehensible sounds, screaming, and at times continual requests for care. In the majority of cases these behaviours are due to damage to the brain and a lack of impulse control (Barton, Findlay, & Blake, 2005; Dwyer & Byrne, 2000; Yusupov & Galvin, 2014). However, it is also frequently related to an unmet emotional or physical need (Mukadam & Livingston, 2012). Shouting and screaming is by no means a new discovery in dementia as they were in fact part of Auguste Deter's Alzheimer's Disease diagnosis (First person diagnosed) made by Alois Alzheimer in 1906 (Kudo, 2016).

Persistent shouting and screaming out is one of the behaviours perceived by nursing staff as most difficult to understand and self-manage when caring for people living with dementia (Palese, Menegazzo, Baulino, Pistrino, & Papparotto, 2009). These stressors can prompt subjective negative interpretation and biased judgements by the nurse which are projected onto the patient and influencing their care (Digby et al., 2016). This in turn leads to the risk of depersonalising and a “deterioration in human relations”, which can only leave both parties emotionally exhausted (Kimura, Tamoto, Kanzaki, & Shinchi, 2011 p.52). All, producing feelings of inadequacy, powerlessness, and at times a sense of being undervalued (Monthaisong, 2018). This non-compassionate nursing behaviour and response could be addressed through training and knowledge by sharing the causal factors of unpredictable or persistent vocalisations, or noises that are

perceived as unwarranted (Edberg et al., 2008). This opens up the question of whether compassion (“the intention to act to relieve the suffering of others”, Hofmeyer et al., 2016 p.202) can indeed be taught (Elsden, 2016; Lee, Laurensen, & Whitfield, 2012; Richardson, Percy, & Hughes, 2015)?

*\*\*He was an angry little man with a balding head, glasses, and a bright red face – I made a noise once in the classroom, the other children laughed. Then the terror began... I am forcefully dragged outside by him and taken to the cloakroom, where I am repeatedly hit and pushed over. I remember being thrown against the coat racks, and once through it. Finally, getting up I hear him scream, “Who do you think you are, stop being such a baby, shut up...and get back in that classroom...”*

3

### **6.3.5 I want you to hear me...**

One way to address our own pejorative behaviour is through self-reflection. Self-reflection allows the person to transform and develop, to allow others to see who they are and to gain insight into the needs of others; it is emotional competence (Liu et al., 2011). However, emotional competence requires not only self-reflection, it also requires self-regulation, which cannot exist without motivation to learn, understand, and change practice when required (Foster et al., 2015).

*\*You wrote that you were mute, and you could not eat... I did not believe you for a second....and so the merry dance began...people told me that they saw you eating and drinking, and yet you wrote that you could not swallow. You were diagnosed with dementia...again that was not what I saw. When I met you, I knew you wanted control of everything, and everyone around you.... I felt hostility towards you when I was with you, and you displayed hatred, an overwhelming contempt for me. You turned away from me when I tried to speak, you put your hand up when I tried to communicate, you made faces, and stuck up your middle finger when I entered the room, you made me feel I had let you down...perhaps I had...You would go missing for hours from the ward, but always come back. All except that once... You really scared that nurse when you wrote telling her you were going to kill yourself, and then waited for me to arrive only to sneak out the door... You did not harm yourself...but I soon realised that my working with you was counterproductive, for both of us... You showed me a side of you, others did not see, and it awakened a side of me I did not like...*

66

"He that has eyes to see and ears to hear may convince himself that no mortal can keep a secret. If his lips are silent, he chatters with his fingertips; betrayal oozes out of him at every pore" (Freud, 1905 in Freud, 1997)

Transference and countertransference were initially the domain of psychotherapy, although it has been acknowledged that it can take place in most care environments (King & O'Brien, 2011). It is "the feelings and wishes often rooted in unconscious childhood experiences redirected toward a new person" (Brim, 2014 para. 2). The outcome of transference can at times be beneficial for the patient, if the transference is a positive experience and managed; however, it is unhelpful in the case of poor childhood parenting, or inadequate role models (Berman & Bezkor, 2010), especially when countertransference is present (Sabo & Vachon, 2011).

*\*\*You should have been my childhood role model... why did you dislike me so much. I tried to connect with you, but you remained distant. I cried, you always told me boys do not cry or feel pain... I knew you hurt too, but you could not tell me. I looked up to you, and you looked down at me. I do not know what I did. I felt the loss you had, felt the pain, held back the same tears. I wanted to know you, hold you, tell you how I hurt, tell you I loved you, but you did not have time...and in the end, neither did I...*

13

Recognising my personal and professional inability to show empathy towards this patient was the first step to making a change to my practice. However, recognising that transference and countertransference was taking place was not immediate (King & O'Brien, 2011). I had considered my own feelings above another, and this was against my professional and personal principles. However, following a long process of reflection, I now perceive this period of countertransference as a temporary "loss of wise mind" (Linehan 1993/1993a; McCallum, 2010) and an opportunity for a new "becoming" or "sense-event" (Deleuze & Guattari, 1987 p.6; Masny, 2015 p.8).

\*\*\* *“Wise mind is the synthesis of the reasonable mind and emotion mind...the middle path” ... “A wise person is balanced”* (Linehan, 2014 p.226 / p.217).

40

### 6.3.6 *Did someone hurt you?*

*\*I arrive on a very busy ward to a very confused elderly woman called Mavis. She is shouting out and writhing around on a trolley. The trolley is raised, and the sides are up; she is in effect restrained. I try to speak to Mavis, but she is forming very few words that make sense, and the tone of her speech and her body language displayed that she is very angry. I crouch down, make eye contact, and gently ask in a calm and gentle manner is there anything we can do? To which Mavis raises her head, spits in my face and shouts, “Fuck off”.*

*Ward Sister: “Can she have more medication, or can we increase the dose”.*

*Ward Doctor: “We need to control this situation”, “she is hurting my staff and the men can’t go near her”;*

*Ward Sister: “She is a nightmare and too disruptive for us to manage”.*

*Staff Nurse: “She won’t let us near her, she is refusing all care...she needs sectioning”*

...

*A couple days later I found out Mavis was placed in care as a young girl following significant sexual abuse, where she was often raped. She married, but again was physically and sexually abused and for a short time was ‘prostituted’ by her partner... it all began to make sense...*

*When I shared the story behind Mavis’s behaviour with the nursing team things rapidly changed for the better...the last time I checked on Mavis she was smiling, she was in a happy place and even offered me a sweet.*

47

*\*\*For I am a human, no different to you.*

*This awful disease, it just makes me so blue.*

*So, with a deep sense of compassion, even if I hit.*

*Remember my suffering and help to relieve it.*

74

Knowing the narrative and history of people living with dementia is key to providing person centred care (Fazio, Pace, Flinner, & Kallmyer, 2018; Kitwood, 1997a). One way to do this is to support the person through reminiscence and life story work (Clarke, Hanson & Ross, 2003; Gridley, Brooks, Birks, Baxter, & Parker, 2016; Thompson, 2011). However, when using life story work with people living with dementia, the general feeling is that distressing events should not be recorded (Kindell, Burrow, Wilkinson & Keady, 2014). It is not a catch all, it is about capturing a brief history of

time and not a biography (Kaiser & Eley, 2016). This however does not address the person living with dementia's distress when they enter a synthesis of the past within the present (Deleuze, 1994). However, as there is no recognised linear pattern to the recollection of traumatising events, supporting the person is often trial and error and a curiosity for other (Rapaport, Livingston, & Cooper, 2017).

*\*\*An angry young man, with issues to spare,  
Trying to reach out and show that I care...  
You saw it in my face and looked deep in my soul,  
Misguided and lost with nowhere to go.  
You challenged 'my truth'; all that I held dear.  
You allowed me to see, to feel and face fear.  
Without our meeting my life would not be the same,  
Please rest in peace, until we meet again...*

8

Not knowing what to do when faced with behaviours that challenge is often a concern for nurses (Clissett et al., 2013; Nunez et al., 2017). This is especially in the case of aggression and violence (Schablon, Wendeler, Kozak, Nienhaus, & Steinke, 2018) where a lack of training and understanding of these behaviours is cited as the main reason (Ervin et al., 2014). In addition, what nurse training is provided is reported to remain inadequate (Timmons et al., 2016).

This is on a background where many admissions to geriatric hospital wards are due to these very behaviours presenting at the pre-admission care provider's residence (Sampson et al., 2014). Although a lack of suitable dementia training is acknowledged as a concern, some studies question the impact of dementia training improving outcomes of behaviours that challenge even when provided (Fossey et al., 2006; Spector, Orrell, & Goyder, 2013). Matthews (2013) found that care provided by specialist mental health units, where training was provided, and specialist skills were present, resulted in little improved patient outcomes or satisfaction compared to normal

hospital care. It is also useful to be mindful that most cases of behaviours that challenge have a primary cause other than the dementia, i.e. delirium, pain, acute /chronic illness, traumatic event recall, and even end of life care issues (Sampson, Blanchard, Denning, Scott, & Jones, 2011; Clissett et al, 2013). These primary causes need to be addressed through tailored and individualised treatments and care plans; much like the secondary behaviours that challenge which present (Moore et al., 2016).

\*\*\* *“People who are at risk of having frequent moments of stress and loss of control often have a long history of conditional and domineering relationships with others”, instead of unconditional and safe relationships. “This creates an increasing fear of others, especially on moments of stress... And these are exactly the moments when they need us the most”* (Gentle Teaching Foundation, nd).

42

### **6.3.7 I won't let them hurt you...**

*\*The telephone rang in the office –*

*Ward Sister: “You need to come quickly, it's all kicking off, George is banging his head against the window and is being restrained by security”.*

*George, who had Lewy Body dementia, had told me a little earlier he wanted to die and had been looking at the windows...he said, “If the glass doesn't kill me the fall will”, this was still ringing in my ears...*

*I entered the ward, breathless and feeling a little inadequate.... George was on his bed with two security guard standing over him 6' 2" plus wearing stab jackets, menacing, and looking somewhere between angry and frightened. George was screaming at the visions in front of him, his eyes wide open and fear evident and palpable. George had his bed sides up, grabbing on and arching his back, grimacing in severe pain. This was not physical pain, this was emotional pain; a mix of delusions, vivid hallucinations, and an indescribable suffering that he could not endure. Beside him a nurse holding his hand and telling him, “He was safe and would be OK”.*

*We moved George to a quieter place, a room on his own and I took over the reassurance, attempted to comfort him. He closed his eyes, but opened them quickly, shouting “get those bastards away, don't let them near me”. ...Just me and George now, I had sent the security guards away and sister went to get medication. But it wasn't just me and George...He told me that at the end of the bed were men in white coats wielding meat cleavers covered in blood and George was next. With time, touch, reassurance, distraction and a tiny amount of medication they went away, as did George's distress and fear... I am exhausted.*

25

Unlike delusions, hallucinations are not commonplace in the early stages of dementia (Linszen et al., 2018). An exception to this is Lewy Body Dementia (LBD) where hallucinations are relatively common (Collerton & Taylor, 2013; Lin et al., 2018; Taylor et al., 2011). However, these hallucinations are not always distressing, and tend to present as children and animals (Zweig & Galvin, 2014). Hallucinations can however relate to past events, including historical traumatic incidents (Hamdy et al., 2017). These distressing presentations are often triggered by co-morbid illness, including delirium and other secondary organic cause; in the case of LBD often the use of neuroleptic medication (Combs & Cox, 2017; Linszen et al., 2018; NICE, 2018).

*\*\*It is a very quick and vicious onslaught. They are merciless and direct in their attack. I am being knocked down again and again and each time picked up and thrown in front of cars...they are trying to drag me under a subway saying, "there's no fucking cameras under there, we can kill him". I hang onto that railing like my life depended on it... it fucking does!*

*Eventually, I am on my hands and knees crawling across the pavement and I hear, "Watch this". I can see him coming towards me, the anger and hate in his piercing blue eyes as he kicks me so hard in the face that I am flipped from a crawling position onto my back, smashing my cheekbone and teeth...my whole body soaked in blood...*

37

The presentation of hallucinations in general nursing settings can be frightening for the nurse; however, if the nurse is curious, calm, attentive, and non-judgmental they can explore the experience alongside the patient (Price, 2016; Roever, 2012). It is also important to validate the patient's experiences, mindful that these perceptions are real for the person experiencing them (Hamdy et al., 2017; Laureys & Tononi, 2011).

*\*\*Hold my hand; I'm scared feel alone,  
My thoughts are jumping; I want to go home,  
Oh Mother protect me, Father I see you so clear,  
But Dementia has grasped me, instilling such fear*

74

### 6.3.8 *I think I've got this...*

By the time I met Philip, I was comfortable and confident in my ability to recognise, assess, and meet the needs of patients living with dementia who presented with behaviours that challenge in the hospital environment, or so I thought. It is important to have a set of skills or nursing competencies in your area of clinical practice, however if you are unable to make situation-specific judgements these competencies will be purely academic (Fukada, 2018).

*\*Every time I walked on the ward Philip would comment on my tattoos;  
Philip: “, I like tattoos they are like mine, were you in the Navy?”  
Me: Yes Philip, I was a Stoker”  
Philip: “Me too, what ships were you on....”  
We would chat about our ships and some of the places we had been. Philip introduced me to his wife Anne – “Anne look at his tattoos there just like mine.... he was in the Navy”  
This would be the conversation we would have each time I arrived on the ward.  
One morning Philip was getting out of his chair to start the conversation and his pyjama trousers fell down...without thinking I stepped forward to pull them up and as I grabbed them Philip hit me across the face...everyone looked at me and Anne looked very distressed and apologised for Philip...  
Me: Sorry Philip, your trousers have fallen down...could I help you pull them back up?”  
Philip: “If you could help that would be good, my back's not good.... anyway, I like tattoos they are like mine, were you in the Navy....”*

54

*\*\*Oh, where on earth am I and hey who are you?  
Why can't I do the things I used to do?  
The lights are so bright here and noises so loud.  
A familiar face I need in the crowd.*

74

This event highlighted to me that I had reached a stage of “unconscious competence” placing me at a risk of not engaging with the patient, or indeed self, before acting (Kelton, 2014 p.711). Which in this case, is exactly what I did to Philip? This was an important reminder to me that competence “represent(s) potential to perform, not actual performance” (National Nursing Research Unit, 2009 p.1). Instead of acting

impulsively, I as a nurse needed my decision-making to be a process of ‘critical thinking, clinical judgement, and clinical reasoning’ (Alfaro-LeFevre, 2016 p.7).

Nurses should be encouraged to exercise professional judgement, but also understand they are responsible for their “actions” and “inactions” (McCartney, 2017; Siewdass, 2017 p.1). Clinical reasoning on behalf of others requires intuition, which is a combination of instinct, expertise, and knowledge (Hughes, 2008) and are all guided by the nurse’s capacity to be metacognitive (Banning, 2008). Metacognition requires the nurse to self-evaluate, develop a sense of self (knowledge), and to have the ability to apply that knowledge to any given situation, whilst making decisions in the best interest the patient (Josephsen, 2014).

*\*\*\*Reflexive meetings helped the nurses to gain awareness of how the accomplishment of patient centeredness was intertwined with taken for granted assumptions and conflictual understandings of patient care....as well as power imbalances (Liberati et al., 2015 p.50)*

67

#### 6.4 Recapping Mapping...

To establish what inferences my sense making mapping had uncovered I completed a final mapping of the findings (recap map). To do this I revisited the six stages of rhizomatic mapping (Table 10 p.79). To produce my recap map I took narrative data directly from the ‘**Making Sense...**’ findings, and my meta-ethnography synthesis and line-of-argument conceptual model (Figure 3 p.38). This nomadic and heterogenic data (Deleuze & Guattari, 1984) was mapped against one another to create a finding recap map (Figure 15) (Leafgren, 2016; McNaughton, 2005). In doing so, there was now an opportunity to develop triangulation between my meta-ethnography and my autoethnography findings, referred to in postmodern qualitative studies as

crystallisation (Ellingson, 2008). Crystallisation takes place when diverse elements of qualitative data and methodologies offer a thick description that does not seek one truth, but many truths (Vik & Bute, 2009). These transient moments are described as becomings throughout my study (Deleuze & Guattari, 1987; Masny, 2013).

This recap map was completed partly to support the development of a concept and nursing model of dementia care in the midst of behaviours that challenge, but also to offer a narrative response to my study aims and objectives. In doing so, I was able to move my thesis and study aim from a passive idea towards a dynamic and realised understanding (Deleuze, 1994; Voss, 2013). However, it is a virtual diagram of what might be; it is and will always “be in the middle...and ...and...and...” (Deleuze & Guattari, 1987 p.27; Sellers, 2015) of intersubjectivity during moments of behaviours that challenge in dementia.

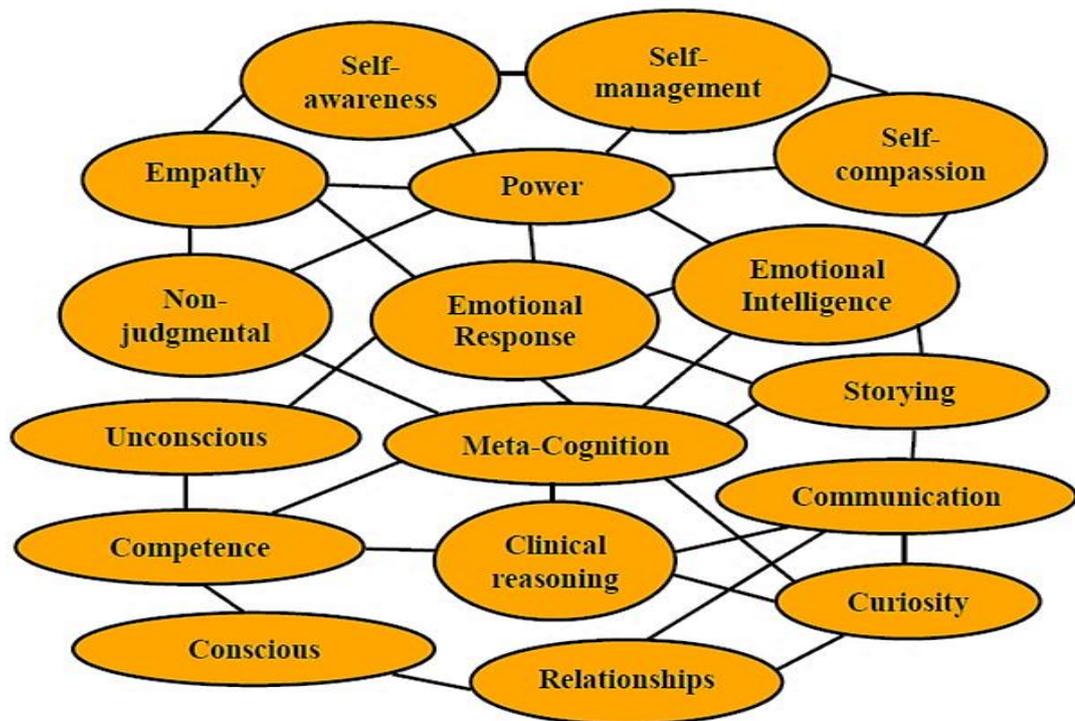


Figure 15 Recap Map

## **6.5 Discussion - The becoming of a conceptual assemblage and nursing model**

**...and ...and ...and...**

### **6.5.1 Introduction to becoming**

This section will initially discuss the becoming of a concept by addressing the points of my sense making and recap maps to shape a concept of intersubjectivity in the midst of behaviours that challenge in dementia. By addressing these points, I will create the foundation of a conceptual assemblage, and then further develop this concept into a nursing model of dementia care in the midst of challenging behaviour in dementia. I will discuss the role of emotion in intersubjectivity for the person living with dementia and me as a nurse during intersubjective moments. As well as emotion I will discuss the role of cognition on a meta-level as a nurse, and the importance of a nurse ('I') being curious about the story behind the behaviours which present in dementia for 'Thou' (Buber, 1970). These are all key (mapped) points which have arisen in my meta-ethnography synthesis and (*re*)mapping findings. All points will be discussed further in the section below.

### **6.5.2 Becoming emotional...**

As previously discussed, my meta-ethnography concluded with a conceptual model which recognises that people living with dementia maintain the ability to be emotionally and relationally intersubjective. Knowing this aided me to understand the importance of the 'I-Thou' (Buber, 1970) relationship in dementia care for positive intersubjective experiences to emerge (Scott, Scott, Miller, Stange, & Crabtree, 2009). I also noted in my meta-ethnography findings that there were more emotional based first order quotes were found in my data than any other quotes (column 1 Table 7 p.31-33). Again, this emphasised the importance of emotions in intersubjective relationships for people living

with dementia. This was particularly the case when cognition or communication is moderately or severely restricted by the type or stage of the dementia (moderate/late stage/frontal lobe dementia). Emotionality was not only a significant presence in my meta-ethnography findings, there was also a noteworthy presence of emotional terms and words found in my ‘**making sense**’ mapped findings. I display some of the terms/words found in my narrative findings in Table 12.

Table 12 *Emotional narrative*

Narrative found in meta-ethnography and rhizomatic mapping				
Alienated	Deprived	Hurt	Loved	Success
Angered	Embarrassed	Inadequate	Pain	Suffering
Belonging	Fearful	Insecure	Pride	Stressed
Compassion	Hatred	Judged	Sadness	Validated
Controlled	Helplessness	Lonely	Scared	Valued
Dependent	Hope	Lost	Shame	

Reflecting on the words found in my data, I noted that many of the words and terms found featured negative emotions. However, I recognised that this may be as my vignettes represented challenging times in the life of people living with dementia, as well as challenging times that I have faced both personally and professionally.

Whilst considering this I was very mindful that these emotions and stories may well feature again later in my life, should I be diagnosed and be living with dementia. My potential becoming future (Deleuze, 1994; Voss, 2013) dementia narrative would place me at risk of entering timeframes in which my living present (drawing on my pure past) would be distressing, not only for others, but also for me (Deleuze, 1994; Voss, 2013). It is my belief that should I develop dementia and present with behaviours that challenge how these moments manifest, develop, and conclude would very much depend on the

intersubjective emotions the care provider and I were experiencing at the time. With the above in mind, the central element of my concept of intersubjectivity in the midst of behaviours that challenge in dementia' became **Emotion**.

### **6.5.3 *Becoming emotional when living with dementia...***

For some, there are longstanding and firmly held beliefs that emotion is always conscious and triggered by physiological arousal; this is known as the James-Lange Theory (Coleman & Snarey, 2011). Psychologist William James and physiologist Carl Lange (James, 1884; Lange, 1912) proposed this theory independently claiming that a physical sensation (shaking) is automatically cognitively determined as an emotion (I am frightened). Those who cite this theory maintain that the process of emotion is driven by neurocircuitry (neural pathways), specifically subcortical and mid brain structures such as the amygdala, hypothalamus, and substantia nigra, and therefore emotions cannot be unfelt (Berridge, 2003; Ousdal, Andreassen, Server, & Jensen, 2014; Minati, 2009; Wendt, Weike, Lotze, & Hamm, 2011). Urabe and colleagues (2017) also offer this organic description of emotion when discussing dementia, noting that atrophy to the amygdala in cases where people living with Alzheimer's Disease presents with anxiety-based behaviours that challenge (Urabe et al., 2017). This loss of function of the amygdala was also found to be present in controlling visual cortex activity restricting the processing of emotions (pleasant and unpleasant) in Frontal Temporal Dementia (Ousdal et al., 2014; Minati, 2009; Wendt, Weike, Lotze, & Hamm, 2011). However, Winkielman and Berridge, (2004) acknowledge that alongside these neurocircuitry processes, there is also the presence of genuinely unconscious emotions. They claim that the effect of these unconscious emotions is strong enough to change the person's behaviour without the person being aware of the presence of the emotion

(Winkielman & Berridge, 2004). Other researchers have since agreed with this finding (Hadzhieva, 2017; Ruys & Stapel, 2008; Watanabe & Haruno, 2015).

Alongside the organic argument of emotionality, others causes cited as factors behind emotionality during episodes of behaviours that challenge in dementia are; personality type, environment and (evocative/distressing) past life events (Dorey, Rouch, Padovan, Boublay, & Salmon, 2018; Kar, 2009; Tible et al., 2017). These are the emotions experienced in that intersubjective moment by the person living with dementia, and me as the nurse supporting them. Whichever model of emotion is referred to by researchers, all agree that the very process of dementia itself leads to people living with dementia perceiving their environment from a different “emotional base” (Mayordomo-Rodríguez et al, p.451). Whatever the causal factor/s, and whether emotion is conscious or unconscious, I have no doubt that the presence of emotion is key factors associated with behaviours that challenge for the person living with dementia. Not only for the person living with dementia, but also the nurse providing the care.

#### **6.5.4 *Becoming un/consciously emotionally intersubjective as a nurse...***

So, what about me as a nurse? I have noted the importance of emotions in intersubjectivity during moments of behaviours that challenge in dementia, and as previously discussed intersubjectivity is a two-way process. So, are all of my emotional responses as a nurse conscious? What did my ‘**making sense**’ rhizomatic mapping of my journal data and findings tell me?

I certainly found that I responded unconsciously in one case, which was represented by in my map ‘*I want you to hear me...*’ (Page 102 - ) “*It awakened a side of me*

*I did not like...*” On reflection, and as a process of data analysis I noted that countertransference was present when I attempted to therapeutically engage with the person living with dementia. This unconscious emotional response was likely to relate to unresolved hurt from the “pure past”, which interrupted with the “living present” (Deleuze, 1994; Voss, 2013). This behaviour blocked any likelihood of a positive intersubjective or therapeutic relationship developing (Dossey & Keegan, 2009), which is certainly the case in my ‘*I want you to hear me...*’ mapping (Page 103 - 13), “*I tried to connect with you, but you remained distant*”. This is where *unconscious* transference and countertransference took place.

Another unconscious action was present in my ‘*I think I’ve got this...*’ mapping, where I had entered a period of (unconscious) competence. This unconscious state led me to behave in a manner that broke down a well-formed and effective intersubjective relationship with Philip (Page 108 - 54). My ‘**making sense**’ mapping and other recollections have led me to believe that during moments of behaviours that challenge my unconscious emotions have placed me at risk of responding with unbalanced or unhelpful behavioural responses, which have generated a negative reaction from the other.

The traditional argument that emotions are conscious led me to ask myself what conscious elements were present in my nurse / person living dementia ‘**making sense**’ and narrative mapping of intersubjectivity during moments of behaviours that challenge? I was of course conscious and aware of Mavis’s emotions in my *Did someone hurt you?* map (Page 104 - 47) and in my journal I reflect on feeling ‘*sad and embarrassed*’ when Mavis spat in my face. Other maps where I was

consciousness of my, and others, emotions included, *I won't let them hurt you...* (Page 106 - 25 ) where I note George's *fear*, the security guards' presentation of *anger and fear*, and my own feeling of *inadequacy*. These are all examples of the presence of conscious and unconscious emotional reactions and response during moments of behaviours that challenge in dementia, and I acknowledge the potential for those emotions to impact on my decision-making.

My '**making sense**' rhizomatic mapping also presents narrative that suggest strong emotions were present in other care providers (nurses) during behaviours that challenge moments where I was asked to assess / offer treatment/support options: 69 Ward Sister's *Anger* stating "*one of yours has shat in my sharps box*", 72 HCA *impatience* at Mary's shouting – "*I can't stand it, she doesn't stop shouting, and it gets on my nerves*"... 47 Ward Sister's *irritation* at Mavis's *behaviour* "*She is a nightmare and too disruptive for us to manage*".

And 25 Ward Sister's *fear* at George hitting his head against the window "*You need to come quickly, it's all kicking off...*" Although my findings indicate that my emotions as a nurse may well have impacted on my decision making, it would be unfair of me to make assumptions of whether these emotions may have affected other nurses/healthcare providers' care provision or decision making.

My study findings indicate that emotion can not only be the triggering factor of an event of behaviours that challenge (Coggins, 2015; Kar, 2009) but can also influence a nurse's initial reactions and retorts when challenged ('I-Thou'). With this in mind my foundational concept acknowledges that how I (as a nurse) respond to the feeling of being challenged could potentially influence the outcome of that intersubjective

moment (Brandman, 1996; Buber, 1970; Bridges et al., 2013). Finally, my findings indicate that although there is not always an obvious trigger to the emotions experienced at challenging moments our stories always a factor in these situations (De Jaegher et al., 2016; Valandra, 2012).

Collectively, my meta-ethnography synthesis, my sense making mapping, and finally my recap mapping has produced and made sense of a collection of heterogenic data to create a foundational concept of intersubjectivity in the midst of behaviours that challenge in dementia. This foundational concept recognised that there was an emotional connection between me as the nurse ('I') and the person living with dementia ('Thou') during moments where behaviours that challenge presented (Buber, 1970). These were moments where we both felt emotion, at times our own, but often each other's. Moments which have formed new but transient becoming's drawn from our pure past and living present stories (Deleuze, 1994; Deleuze & Guattari, 1987). Finally, my finding suggest that the outcome of our intersubjective moment is dependent on how these emotions/stories connect, converge, and at times clash (Deleuze, 1994; Kitwood, 1997a; Voss, 2013). My foundational concept of intersubjectivity in the midst of behaviours that challenge in dementia is shown in Figure 16 below, and is discussed, explored, and developed further in the following section.

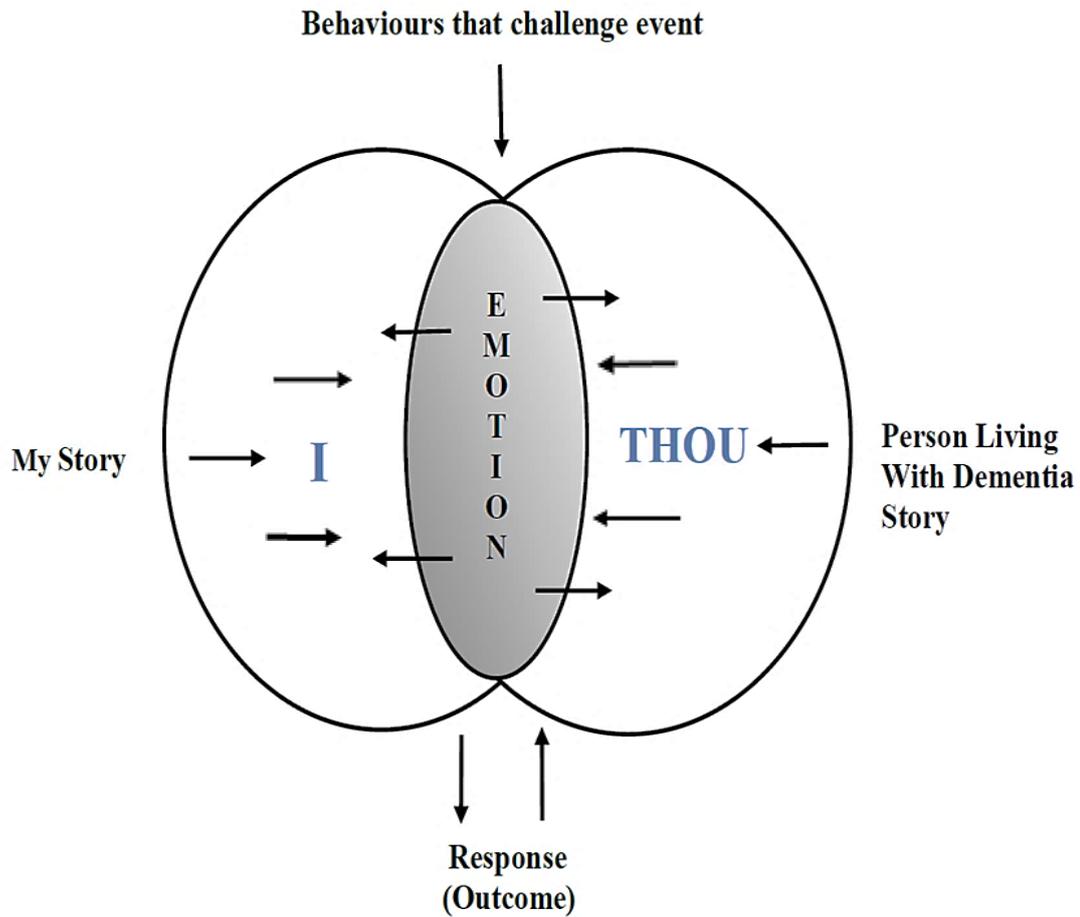


Figure 16 Foundational concept

To develop my foundational concept into a fully constructed intersubjective nursing model of dementia care I revisited my findings. In doing so I addressed the areas that had not yet been discussed or represented in my foundational concept. These were: self as a nurse (adapted) and as a person (experiential), metacognition in nursing (thinking about thinking), empathy and curiosity, and finally nurse power versus empowerment of other.

### 6.5.5 *Becoming my adapted self (nurse) through my experiential self*

One way for me as a nurse to address any unhelpful or negative responses to a person living with dementia is to become more aware of my sense of self, and in turn, my

emotional triggers (Bramley & Matiti, 2014; Jack, 2012; Haley et al., 2017). It is argued that our emotions and perceptions affect our responses and thought processes in a variety of personal and social contexts (Zeelenberg & Pieters, 2006). It is therefore perceivable that behaviours of others, particularly those which are perceived as challenging can instigate emotions, sensations, and thoughts within us (Cosmides & Tooby, 2000). However, these feelings and emotions are adaptive and can evolve through: experience, shifting perceptions, informed decision making, and newly developed response behaviours (Haselton, & Ketelaar, 2005). This nevertheless requires the presence of self-reflection and self-awareness in nursing practice (Langley & Brown, 2010). And, in the case of my study the engagement with my adapted self through my experiential self (Kitwood, 1997).

However, for nurses to be person-centred and compassionate it is incumbent on nursing organisations to allow time and space for self-evaluation, reflection, and reflexivity into nursing practice, which is best supported by using case studies (Josephsen, 2014; Liberati et al., 2015). Using case studies to reflexively consider nurse/patient experiences and relationships allows time and space for the nurse to reflect and self-evaluate, and in doing so they are able to reconsider their coping strategies (Koshy, Limb, Gundogan, Whitehurst, & Jafree, 2017). This form of reflection leads to an improved quality of care, and professional growth (Foster et al., 2015; Oflaz et al., 2011; Pai, 2015). It has however been argued that suggesting nurses engage in reflective practice solely for the purpose of change is covertly coercive, as it implies that the nursing practice provided is currently insufficient or ineffective (Jack, 2012). Nevertheless, evidence does indicate that self-awareness through reflection in and on practice will improve insight into patient care, and reduce nurse stress (Haley et al.,

2017; Horton-Deutsch, & Sherwood, 2008; Pai, 2015). Jack (2012) argues that nurses need to engage and understand their own emotions before they are able to engage with patients in anything more than just a superficial level.

My study methodology and processes committed me to self-inquiry, all of which was through making sense of my position in relation to others when behaviours that challenge presented. However, to engage in this process of subjective understanding, within intersubjective moments, I needed to make connections with others on a deep and empathic level (Clark, 2014; Rogers, 1975). Although one cannot wholly experience another's subjectivity, self-perception is facilitated by the encountering, engaging and understanding of other (Krueger, 2013).

#### **6.5.6 *Becoming a Metacognitive Nurse***

Whilst engaging in my findings I noted that at times I was acting impulsively. These instinctive and emotionally driven practices often led to negative outcomes and behaviours. I concluded from this that when faced with challenges and needing to make a decision I not only needed to attend to what I felt, but also what I knew. Nurse decision-making requires a process of "critical thinking, clinical reasoning, and clinical judgement" (Alfaro-LeFevre, 2016 p.7); all facilitated by the implementation of metacognition. Metacognition requires the nurse to self-evaluate, develop a sense of self (knowledge), and to have the ability to apply that knowledge to any given situation (including challenging moments) (Josephsen, 2014; Kuiper & Pesut, 2004) whilst also making decisions in the best interest the patient (Josephsen, 2014). This can be supported by incorporating active listening and self-awareness into nursing practice, which in turn promotes empathy and person-centred care guided by the curiosity for

other (person living with dementia) (Haley et al., 2017; Rapaport, Livingston, & Cooper, 2017).

When metacognitive self-analysis, self-awareness, and critical thinking skills arose in my findings I wondered whether the people I was supporting with dementia continued to have this cognitive capacity. One of the key points which arose on the subject was the reduced ability for people living with dementia to be self-aware (Bertrand, Landeira-Fernandez, & Mograbi, 2016; Mograbi, Brown, Landeira-Fernandez, & Morris, 2014; Sunderaraman & Cosentino, 2017) and also aware of the abilities of others (Mograbi, Brown, Landeira-Fernandez, & Morris, 2014). These absences in awareness of self and others are present in all forms of dementia, but more evident and severe in Frontal Temporal Dementia (Eslinger, 2005; Fernandez-Duque & Black, 2007; Rosen, Alcantar, Shimamura, Neuhaus, & Miller, 2014).

The loss of these metacognitive processes is additionally problematic when the person living with dementia presents with behaviours that challenge, as they are unable to self-appraise (Bertrand et al., 2016). This indicated to me that as a nurse I needed counteract this inability for the person living with dementia to self-appraise by making a metacognitive effort on behalf of both of us. This is the only way for empathy for other to exist (Stansfield et al., 2015). Nevertheless, for this effort to be reflexive in my practice (as inferred in my findings) I need to move my position as a nurse from a “self-centredness toward an other-centredness”, leading to a curiosity for other to produce an empathic understanding (Eichbaum, 2014 p.71).

### **6.5.7 *Becoming Empathically Curious***

When I put myself in another person's shoes it allows me as a nurse to get to know another and establish a compassionate connection (Bramley & Matiti, 2014). However, I found that I needed to go a step further than just being compassionate. I found that to respond effectively and create a positive intersubjective outcome I needed to not only feel what the person felt, but also be curious about that feeling, and the meaning behind presenting behaviours. This is described by McEvoy and colleagues as empathic curiosity (McEvoy, Baker, Plant, Hylton, & Mansell, 2012; McEvoy, & Plant, 2014). Empathic Curiosity is a method of meta-communication (Bateson 1973) guided by (social) control theory, which states that behaviours are internal conflicts driven by goals and needs (Hirschi, 1969, 1977; Powers, 1973). My vignettes include examples of this drive to meet a need and the internal conflict, which presented as behaviours; these include '*Are you Serious*'? And, '*Are you sure you should be doing this*'? Here something as simple as a person expressing their need to open their bowels became problematic, arguably due to the way this need was managed; without empathy or curiosity for other.

The capacity to attend to another person requires one to not only listen (Rogers, 1975) but to also absorb and hold onto the emotional experience of the other pro-socially (Zaki & Ochsner, 2012). McEvoy and Plant (2014) found that when one can be curious in dementia care by asking short and open (past tense) questions, picking up on emotions, communicating respectfully, and using metaphors, one can improve the relational space between healthcare professionals and person living with dementia. To be empathically curious also somewhat addresses the potential of power imbalances (Liberati et al., 2015) as the emphasis is to share the responsibility of communication between the nurse

and the person living with dementia (Digby et al., 2016). These nurse / patient power imbalances were evident throughout my reflexive maps. These include ‘*Will you just shut up?*’ And, ‘*Are you sure you should be doing this?*’ These mapped examples produced narrative where not only was the need unmet, it was not even acknowledged by the nursing team.

### **6.5.8 *Becoming Empowering***

People living with dementia are often socially disempowered (Svanström, Sundler, Berglund, & Westin, 2013) and this is evident in my findings. An example of which is in my, ‘*I think I’ve got this*’ map, where I instinctively and unconsciously pulled up Philip’s trousers  instead of asking if he needed help. A consequence of this was Philip hitting me across my face. This practice was described by Tom Kitwood (Kitwood, 1990, 1997) as malignant social psychology, as I had disempowered and infantilized Philip by my chosen actions/behaviour. To address this, I acknowledged my mistake to Philip and empowered him to make the decision on how to proceed.

Power in nursing care should be a two-way process, especially as power is not just about the influence of control, but also about getting things done and care needs met (Manojlovich, 2007). Therefore, if the nurse is not empowered to make decisions by their organisation and is restricted by task / time orientated care provision the likelihood of them meeting an individual’s needs is compromised (Scales et al., 2017). Nevertheless, it is inevitable that the nurse will need to lead the way towards providing an empowering environment and relationship (Scott et al., 2009) whether this be supported by their leadership, or not (Mudallal, Othman, & Al Hassan, 2017). And, in doing so the person living with dementia will be valued, preserving a sense of self-worth within a cognitively stimulating setting (Tranvåg, Petersen & Nåden, 2013). This

will in turn create a balanced relationship built on mutual trust and respect for one another (Ericsson, Kjellström, & Hellström, 2011; Flesner & Rantz, 2004).

#### **6.6 Becoming a conceptual assemblage and nursing model of dementia care in the midst of behaviours that challenge**

“There is no heaven for concepts. They must be invented, fabricated, or rather created and would be nothing without their creator’s signature” (Deleuze & Guattari, 1994, p. 5).

To move towards the development of my conceptual assemblage (Deleuze & Guattari, 1987) and nursing model of intersubjectivity in the midst of behaviours that challenge in dementia I needed complete immersion in my data. This immersion took place during data collection, whilst analysing, and also by plugging into my findings (Deleuze & Guattari, 1987) at differing points throughout the study. In doing so I explored the intersubjective gap and sought to make sense of the intersubjective nuances that occurred in the moments where behaviours that challenge in dementia presented; including my place within those moments. Covey (2004 p.68) refers to the space, or gap between the event and the decision to act, as the space that exists between “stimulus and the response”, the space where complex narratives, emotions, and experiences reside (Bangou, 2019). These moments are often instigated by our needs, wants, and emotions, and an attempt to communicate these things with one another. This is the case for the nurse as well as the person living with dementia. However, the findings indicate that although there are common points of reference, every incident of behaviours that challenge is different, because we are all different.

Within the intersubjective experience there is the story of ‘I’ and ‘Thou’ (Buber, 1970), which at times is part the problem, especially when our stories collide. However, I noted

that when I metacognitively self-managed those experiences I became curious about other; the, 'Thou' behaviour, 'Thou' emotion, 'Thou' need, and the 'Thou' story. I was then able to help and achieve a more positive outcome to the intersubjective experience, as my decision making was more informed. In doing so I was able to witness the things that took place in the midst of the behaviour in the *in medias res*, not only as an outsider, but also an insider. In doing so, I was able to move my foundational concept of 'intersubjectivity in the midst of behaviours that challenge' into a fully constructed nursing model of dementia care that I can use in practice.

### **6.7 Becoming a nurse's model of practice...**

My thesis findings highlight that my emotional and behavioural responses as a nurse towards a people living with dementia in the midst of a behaviours that challenge moments often had an impact on the intersubjective outcome or our experience. As a nurse, I was also mindful of that the person living with dementia also potentially had a reduced capacity to maintain their own subjective agency (Higgs & Gilleard, 2016) due to the nature of dementia. It is therefore incumbent on me as a care provider to do everything I can to support them in maintaining that agency (Rodriquez, 2009). However, as discussed throughout my study there is no simple answer, it is complex and multifaceted; a rhizome of issues, a kaleidoscope of ideas.

I had created a story of what 'I' as a nurse have found to be important in building and sustaining a therapeutic and positive intersubjective relationship in moments of challenge. This is a story created from the times when my experiential ('I' - nurse) story collided, clashed, or combined with the living present or pure past of 'Thou' (person living with dementia) (Buber, 1970; Deleuze, 1994; Kitwood, 1997a; Voss, 2013).

These were moments where we both felt emotion, at times our own, but often each other's to form new but transient becomings (Deleuze & Guattari, 1987). I had however concluded that to build and sustain a therapeutic and positive intersubjective relationship in moments of challenge 'I' not only needed be meta-cognitive, but also empathically curious during moments of behaviours that challenge. I therefore needed to understand what my (subjective) nursing cognition and behaviour would need to be during the intersubjective moments to achieve a positive outcome for 'I-Thou' (Buber,1970) during behaviours that challenge moments.

### **6.7.1 *Becoming a nurse's cognition and behaviour***

As noted, I was now aware of the need to be meta-cognitive but also empathically curious during moments of behaviours that challenge to build and sustain a therapeutic and positive intersubjective relationship in moments of challenge. Nevertheless, how I would do this required further reflection. I asked myself what could I actually do cognitively and behaviourally as nurse to achieve a positive outcome for 'I-Thou' (Buber, 1970) during these intersubjective moments? To make sense of this, and to remain congruent to my study I completed a rhizome map of 'what could I ask 'self / other' in a moment of behavioural challenge, and what I would be curious about'?

I have placed these mapped metacognitive and empathic curiosity findings in a linear tabular form (Table 13), partly to aid the reader and to be transparent, but also to support the development of my nursing model of care. However, as these suggestions were created rhizomatically I would also need to be apply them rhizomatically due to the nomadic nature of thoughts, emotions, and behaviours I have found to exist in

intersubjective relationships (Deleuze & Guattari, 1987; Deleuze, 1993; Honan & Sellers, 2006).

Table 13 *What can I do as a nurse?*

<b>Be Curious...</b> (empathic curiosity)	<b>Think about your thinking...</b> (metacognition)
About self (story) About other (story) About emotion (self & other) About need (self & other) About behaviour (self & other) About communication (self & other) About the outcome (positive/negative)	Who am I and how can I help? Who are you and how did you get here? Why do I / You feel this way? What do I/you need? Why do we need it? What has led to (perpetuates) your/my behaviour? What are you trying to tell me? How can I hear you? How did I resolve this? What did I learn?

My mapping and subsequent Table concluded that to create the possibility of positive intersubjectivity during moments of challenge I first I needed to be curious; not only about the person living with dementia, but also myself, both experientially and within my adapted role as a nurse. That is the only way I can see that I would be truly empathic; as nursing empathy will not exist without a sense of self (Chowdhry, 2010; McLaren, 2013). Carl Rogers (1995) expresses that empathy is not only understanding the meaning and emotion of other, but also tapping into an unconscious; a place beyond the others awareness. This is where the connections are to be made between me as a nurse and the person living with dementia.

Secondly, I was already aware, but became even more aware throughout my study that the person living with dementia could be at times be cognitively reliant on me as a nurse. This required me to be metacognitive (Banning, 2008) for the moments when I need to think on behalf of the combined 'I and Thou' (Buber, 1970). Times, when perhaps the person living with dementia is not aware of their behaviours or feels insecure in the hospital environment and needs my support or guidance (Horning, Melrose, & Sultzer,

2013; Hung et al., 2017). This can only take place in combination with my being empathically curious, as without this I risk disempowering the person living with dementia. However, I must always give 'Thou' the lead and do what is in your best interest (Department for Constitutional Affairs, 2007).

To summarise, there is a need for me as a nurse to be empathically curious and metacognitive during moments of behaviours that challenge as emotions are heightened, and pure past stories are unfolding. To acknowledge this, I propose an intersubjective nursing model of dementia care in the midst of behaviours that challenge (Figure 17). The model recognises the role of emotions and story as discussed in my concept of intersubjectivity in the midst of (*in medias res*) behaviours that challenge in dementia - (Figure 16 page.118) but is also guided and developed further by the findings reported in Table 13 which represents what I can think and do as a nurse to support positive intersubjectivity during moments of behaviours that challenge in dementia. I have named this model my Meta-Dementia Nursing model (Meta-DemNurs) as not only is the model asking me as a nurse to be metacognitive, arguably it is also asking me to be deeply self-reflective and curious, so therefore also meta-empathic (Bergin, 1998 cited in VanKatwyk; 2006; Hoffman, 2001). All of which will produce personal and professional growth and learning through the process of becoming other.

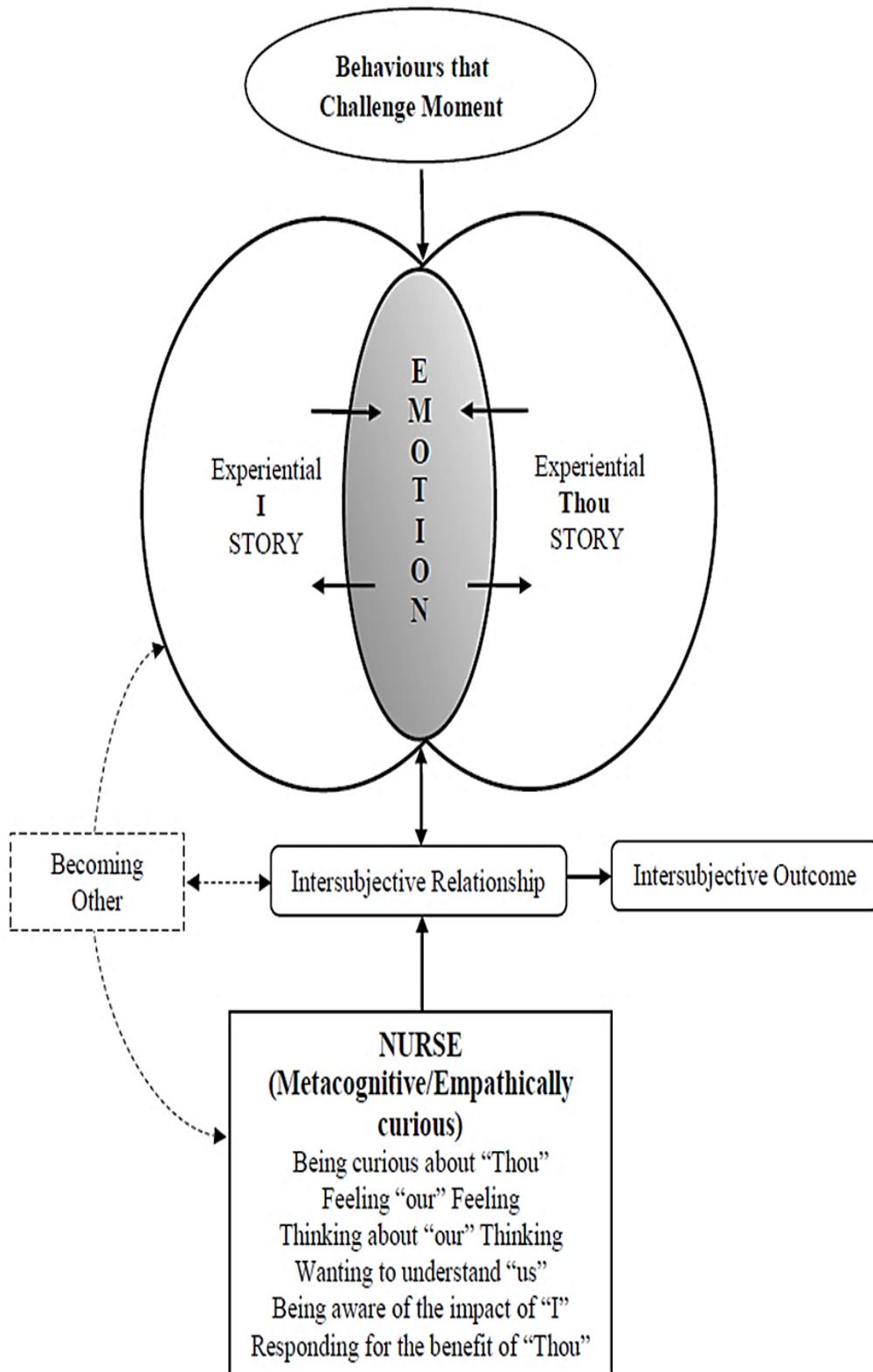


Figure 17 (Meta-DemNurs) Model

## **7 Chapter 7 - Implications of becoming an intersubjective conceptual assemblage and nursing model...**

### **7.1 Introduction to chapter**

My thesis has used autoethnography as a methodology to explore my story of becoming intersubjective in the midst of (*in medias res*) of behaviours that challenge in dementia framed within a Deleuzian theory of time, where the pure past, meets the living present, creating a transient becoming future synthesis. To begin, I first completed a meta-ethnography literature synthesis that concluded that people living with dementia continue to have the capacity to be intersubjective, if not always on a cognitive level on an emotional level. Once I had established the presence of intersubjectivity was present for people living with dementia I set out to:

1. Make sense of my experiences of intersubjectivity in the midst of behaviours that challenge in dementia.
2. To understand whether my experiences of behaviours that challenge have influenced my decision making or capacity to support a person living with dementia during challenging moments.
3. Consider how I as a nurse can manage the intersubjective dynamic that arises in the midst of behaviours that challenge in dementia to achieve a positive outcome for both parties.

My study has used retrospective reflexivity to record experiential multimedia data (personal and professional) within an electronic journal. This data was then analysed using rhizoanalysis in the form of rhizomatic mapping to consider the aims above. Once analysed, my study produced a conceptual assemblage of intersubjectivity in the midst

of behaviours that challenge in dementia and a personalised dementia nursing model of care (Meta-DemNurs).

This chapter seeks to answer the question of how my conceptual understanding and nursing model of intersubjectivity in the midst of behaviours that challenge could connect to my transitory becoming future. This includes how these concepts and models could be used in my practice, and how they could be explored in future research. The chapter also seeks to answer questions around the rigour and limitations of my methodology and data management methods. And finally, it discusses my struggle with balancing the expectations rules of a conventional PhD thesis within my transitory and free flowing methodologies and writings.

## **7.2 Applying a nurse's model of practice...**

My nursing dementia model acknowledges that emotions and pure past stories will be present during challenging moments and suggests the use metacognition (via empathy / curiosity / self-awareness) to explore these emotions/stories in order to support the person presenting with behaviours that challenge in dementia. This model is by no means an answer to all events where behaviours that challenge present. Nevertheless, it does offer a set of behaviours and cognitions that could be considered by a nurse ('I') during that "stimulus and the response" moment in time (Covey, 2004 p.68) and the moments of reflection that follow.

This is the time where 'I' as my adapted nurse and experiential self in my living present meets the experiential 'Thou' as a person living with dementia in your pure past; a moment where our meeting will create a new and combined transient becoming future

(Buber, 1970; Deleuze, 1994; Kitwood, 1997; Voss, 2013). And, if in those moments I am to remain curious and able to honour the ‘Thou’ in the intersubjective exchange I believe we are more likely to reach a combined positive outcome. However, for the model to be tested and applied outside of my own ‘self-practice’ the model would require a process of assessment, evaluation, and a subsequent training package would need to be developed. This process of assessment, evaluation, and training could potentially be developed and tested in a future qualitative study.

### 7.3 **Becoming Research...**

Initially it was my intention to use either (nursing) action research or pure ethnography as a methodology in which to learn from others, and then consider making changes directed by team-based learning. However, on reflection felt I needed to explore the ‘I’ in this experience, before I took the findings to other nurses and considered other methodologies. Now that I have completed my self-exploration and concluded with a model of nursing in dementia (Meta-DemNurs) any future research would need to consider a self-practice model of nursing could be transferred and evaluated across a wider nursing cohort. And, as discussed in my *applying a nurse’s model of practice...* section to do this would also require the development of a training package.

Therefore, I propose taking my study’s findings and my Meta-DemNurs model to a dementia care nursing environment in order to discuss and review the model, making changes as required, with the aim to eventually creating a training package. This process will consider the potential of using metacognition and empathic curiosity when supporting people presenting with behaviours that challenge in dementia. The methodology of choice for this process would be Participatory Action Research (PAR)

(McIntyre, 2008; Whyte, 1991). This PAR process would commence with workshops / focus groups with a team of adult nurses who work in care of older adult wards in a general hospital assessing, evaluating, and testing the Meta-DemNurs model. From the data collected a further series of workshops would consider training needs (analysis), consider appropriate resources and develop a training programme. This would be followed by a pilot study and further evaluation.

#### **7.4 Becoming a conceptual & nursing model conclusion...**

In conclusion, my concept and (Meta-DemNurs) nursing model of dementia care acknowledges that the emotional and behavioural transference between a nurse and a person living with dementia in the midst a behaviour that challenges moments are key factors in the intersubjective outcome. These emotions and behaviours are at times unconscious, and at other times, particularly in my case as a nurse conscious. These emotions and behaviours arguably can arise from cerebral neurocircuitry, but alternatively the event itself, life experiences, the environment, and perhaps most significantly our story ('I-Thou') (Deleuze, 1994; Voss, 2013); all real living is meeting" (Buber, 1970 p.11).

Whatever the mechanism of the emotion and behaviour, I have recognised that *in medias res* I (as a nurse) will always be becoming-other during these events, as no situation, response, or outcome will ever be the same (A Kaleidoscopic moment). However, to become other in the moment 'I' need to be, curious about 'Thou', use metacognitive skills to assess and process my thoughts to face my own challenges more effectively. 'I' need to validate the emotions of 'Thou', and perhaps most importantly 'I' need to acknowledge our stories are different and diverse. New stories arise each

time a behaviour that challenge moment occurs in the living present (Deleuze, 1994) due the response and reaction to and from the person living with dementia and the nurse; all adding a new chapter to the story. The new chapter is created in a place where, “*I/Thou* were the narrative/s, *I/Thou* were the adjective/s, but *we* were the overall story” (De Jaegher et al., 2016, p.509).

Deleuze argues that amongst our multiplicities of “lived experience” there is both individuality and diversity (Deleuze, 1994 p.154). These paradoxical states of being can interconnect, and yet at the same time disperse, all through transitory lines of flight which allows the construction of “new possibilities of life”, produced though new “sense-events” that allow new “becomings” to emerge (Deleuze, 1994; Deleuze & Guattari, 1987; Smith, 2012.p.72; Masny, 2015 p.8). These newly found becomings produce a space in which the temporary can be transformational, and where the “fabric of the rhizome” allows transient musings and writings of “and...and...and...” which when embraced permit the overlapping of difference in self, other, and the virtual (Deleuze & Guattari, 1987 p.27; Sellers, 2015). This process of immanent interaction of the virtual and the actualised can repeat, and all new becomings will be different (Deleuze & Guattari, 1987; Masny, 2015). Therefore, the immanent weave of the virtual into the actual will always create a new pattern (Bangou, 2019). This is displayed in Figure 18, which was a photo taken on a family day out, whilst I mused about what this all meant!



*Figure 18* My understanding of the “Fabric of the rhizome”

I must note that my conceptual assemblage of dementia nursing care in the midst of behaviours that challenge is not isolated from any other concepts that may arise, either by me as a the researcher, or by the reader, as all concepts created through rhizoanalysis interact and blend with one another (Masny, 2013, 2015, 2018; Sellers, 2015; Strom & Martin, 2013). However, for now this process has concluded with the creation of a new dementia nursing model (Meta-DemNurs). This model was created by new “sense-events”, “assemblage”, and “becomings”, all forming a new kaleidoscopic image made up of fragments of our stories; all of which embraced difference and repetition (Deleuze & Guattari, 1987; Deleuze, 1994; Masny, 2015 p.8). A model that allows my temporary “becoming” to be transformational “and... and... and”.... (Deleuze and Guattari, 1987, p.27).

## 7.5 Implications of becoming a thesis...

As mentioned throughout my discussion chapter, although my rhizomatic mapping has offered new knowledge through a sense making assemblage of intersubjectivity in the midst of behaviours that challenge, it does not propose to be a fixed truth (Deleuze & Guattari, 1994). I also acknowledge and accept that any assemblage concepts that arose through my thesis were not from an isolated 'I' (Deleuze & Guattari, 1987; Masny, 2018) but were instead a “collective assemblages of enunciation” (St. Pierre, 2017 p.607).

My assembled concept and dementia nursing model (Meta-DemNurs) were created by ‘actual’ retrospective (past) reflexive practices which took place in moments that were my living present. However, as I write, and you read, they have already become ‘virtual’ again by the passing through, shifting, transforming, and combining through lines of flight and other concepts (Deleuze, 1994). Deleuze described these concepts as, “non-pre-existing concepts within time” (Deleuze, 1984; Smith, 2013 p.381; Williams, 2011 p.205). What I share from my thesis is a fluid process of my becoming intersubjective in the midst of behaviours that challenge in dementia; a concept and model which will change over time. A concept and model that embraces the theory that knowledge can come from disorder and disarray; “chaos is characterized less by the absence of determinations than by the infinite speed with which they take shape and vanish” (Deleuze & Guattari 1994 p.42). However, is it chaos or kaleidoscope...? (Robinson, 2017).

## 7.6 Becoming rigorous...

On a background of criticism of autoethnographic research methodology (Allen-Collinson, & Hockey, 2008; Denshire & Lee, 2013) it is unavoidable not to acknowledge that the study is focused on self, where I was the researcher and the researched (Doloriert and Sambrook, 2009). There is therefore a reliance on the researcher to shape the data collection and analysis into a form in which the reader can see how they match with the findings. This reflexive approach to the study is the only way in which rigour and trustworthiness can be ensured in autoethnography (Etherington, 2004). Le Roux (2017) concluded that for autoethnography to be rigorous it could be measured against five criteria presented in Table 14 below:

Table 14 *Autoethnography Rigour appraisal criteria developed by Le Roux (2017)*

Autoethnography Rigour	My Study Rigour
1. Subjectivity: The self is primarily visible in the research.	Self is visible throughout the study – e.g. The use of ‘I’ vignettes, narratives, and other multimedia data including images and poetry represent subjective story telling.
2. Self-reflexivity: There is evidence of the researcher’s intense awareness of his or her role in and relationship to the research	Self-awareness/self-discovery issues/narratives such as emotional engagement and transference are addressed throughout the study. ‘Self’ as a concept is captured in a culture-gram (Figure 9)
3. Resonance: the audience is able to enter into, engage with, experience or connect with the writer’s story on an intellectual and emotional level.	Vignettes include personal experiences, emotions, and narrative – the study uses emotive and analytical methods of autoethnography to offer a layered account.
4. Credibility: There should be evidence of verisimilitude, plausibility and trustworthiness in the research.	All personal narrative/vignettes are a factual recall of real events (lived experiences). However, to protect others names are changed and details anonymised.
5. Contribution: The study should extend knowledge, generate ongoing research, liberate, empower, improve practice; autoethnography teaches, informs and inspires.	Both clinical and research suggestions have been discussed in the <i>Becoming Practice...and Becoming Research...</i> sections of my thesis. The study highlights the capacity of a nurse to influence the experiences of people living with dementia by using metacognition and empathic curiosity.

I believe, as evidenced Table 14 that my study meets all of the criteria suggested.

However, as previously discussed it is for the reader to finally decide if I have been truly open, honest and reflexive (Ellis, 2000; Ellis & Bochner, 2000 McIntyre, 2008).

## **7.7 Limitations...and...and...and...**

### **7.7.1 *The rules over becoming a thesis...***

I have acknowledged that some researchers consider autoethnography to be self-absorbed, intellectually lazy, and even narcissistic (Atkinson, 2015; Delamont, 2007, 2009; Roth, 2009). This has not been my experience, and like others (Anderson, 2006; Chang, 2008; Denzin, 2006; Ellis, 2004; Ellis & Bochner, 2000; Vryan, 2006) I do not feel lazy or in any way a narcissist for seeking to explore self in the world as part of research study (Zempi, 2017). In contrast, advocates of the methodology challenge this self-absorbed and idle rhetoric firmly by describing autoethnography as research methodology that explores multiple levels of awareness which reside between the individual and the culture of interest (Denshire, 2013; Ellis & Bochner, 2000). Autoethnography is not only a process, it is also a product, which when paired with other research methods can offer a “borderland between passion and intellect, analysis and subjectivity, ethnography and autobiography, art and life” (Behar 1996, p.174; Grist, 2013). I believe my study has met this expectation by making connections between self, other, time, space, the temporal and the cerebral, all in a layered argument, incorporating both analysis and an evocative text, through autoethnography and rhizomatic analysis.

I am also very aware that my study’s methodology and data method is controversial and perceived as non-conventional. Rhizoanalysis was described by Masny & Cole as a

“(non-) method” (2012 p.32). They do however acknowledge that this is due to there being no correct way to do rhizoanalysis, which has led to a number of approaches being promoted or produced as best practice (Leander & Rowe, 2006; Masny & Cole, 2014; Masny, 2015; Sellers, 2015; Strom & Martin, 2013). Nevertheless, to be a rhizoanalysis the process should always include a heterogenic multiplicity of “transgressive and decentred” lines of connectivity and rupture, all of which can produce an assemblage, or a new map of becoming (Deleuze & Guattari, 1987; Cole & Masny, 2012 p.32; Masny, 2018).

Rhizoanalysis in the form of rhizomatic mapping offered me freedom, but also the challenge of being fully immersed in my data collection and analysis processes, taking me to a place many other method/ology’s would not. Rhizoanalysis as an approach allowed me to abandon any expectations and preconceptions, allowing me to immerse myself in the data systematically, immanently, and yet empathically (Masny, 2014). Nevertheless, I acknowledge that the data in which I immersed myself was a personal narrative, and therefore any conclusion or findings can be argued to be limited and subjective (Méndez, 2014). This however is a weak argument as autoethnography does offer a connection to the culture researched (Holt, 2003). Autoethnography also offers the opportunity for that culture to emotionally engage in the narrative findings, making up their own minds about their value against their own sociocultural construction (Ellis, 2000; Ellis & Bochner, 2000 McIntyre, 2008; Spry, 2001). My thesis is my truth, in a world in which “objective reality can never be captured. I only know it through representations” (Denzin and Lincoln, 2000 p. 5).

## 7.8 Concluding comments...and...and...and...

I chose an autoethnography methodology to explore, make sense, and tell my story of intersubjectivity in the midst of behaviours that challenge in dementia. I did this through a process of self-inquiry by recording experiential data, reading, and rereading that data, and then finally rhizomatically mapping a series of personal memories and reflections of moments associated with behaviours that had challenge. These were moments that had challenged me/others during the four years I worked in a mental health liaison service in a general hospital. Nevertheless, my self-inquiry did not stop there, as I also layered my study with personal memories of challenging moments outside of nursing and associated literature, documents, and policy on the subject. These methods of data management allowed me to connect to a wider nursing, social, cultural narrative, and understanding of behaviours that challenge (Ellis, 2004; Ellingson & Ellis, 2008). This methodology allowed me time and space to make sense of the complexity of behaviour and the stories of behaviours that challenge in dementia. And, in doing so, I found I had the freedom to be nomadic and make connections between my story and others, always acknowledging, but also accepting and embracing difference (Deleuze, 1994).

My study has taken variety of mediums and methods framed within a Deleuzian theory of time, where the pure past meets the living present to create a transient becoming future synthesis. These diverse and different mediums and moments have combined creatively to paint a composition of becoming intersubjective *in medias res*. I too have painted that becoming as a self-portrait (Figure 19) which I started at the beginning of my thesis. It is a time-image, made up of relationships between all of its elements (canvas, paint, brushes, and memories) all made up in differing moments in time (Deleuze, 1989; Deleuze, 1994). In the background is a ship on which I served in the

Royal Navy. It is sailing away towards the horizon (pure past). Over my shoulder are rhizome lily plants, both with the same name as the ship I served on (living present). Here, my self-portrait makes metaphorical connections between my pure past and my living present (Deleuze, 1994). I also represent a space in which self is not yet complete, leaving me as the artist/researcher space and time to become future (Deleuze, 1994; Voss, 2013). This is the space where behaviours that challenge in dementia met with my rhizomatic learning style. A space where I have, and can, learn more about self and my subject of behaviours that challenge in dementia, perhaps by engaging with my Meta-DemNurs nursing (self) model. My self-portrait is a metaphor and representation of my thesis and the concepts within.



Figure 19 Self-portrait time image.

Whether I have succeeded in my attempt to make sense of *Becoming Intersubjective in medias res of Behaviours that Challenge in Dementia* will not be solely my decision. Very much like my study methods, I will always be in the *in medias res*, and therefore

I will continue to make connections between self and other; through my PhD supervisors, conference presentations, my viva panel, and finally if published, the reader. Autoethnography and rhizoanalysis have allowed me as the researcher, and the researched, to open up the possibility of new becomings (Deleuze & Guattari, 1987: Masny, 2015). In doing so I have found and presented the messy and complex “world out there” through my eyes (Masny, 2015 p.12: Sellers, 2015). I will now extend that offer to the readership. “The world is not comprehensible, but it is embraceable: through the embracing of one of its beings” (Buber, 1958 p.51).

## References

- Abraha, I., Rimland, J. M., Trotta, F. M., Dell'Aquila, G., Cruz-Jentoft, A., Petrovic, M., & Cherubini, A. (2017). Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop series. *BMJ Open*, 7 (3): e012759. doi:10.1136/bmjopen-2016-012759
- Adams, T. E., Holman, J. S., & Ellis, C. (2015). *Autoethnography*. Oxford: Oxford University Press.
- Affleck, D-C. (2019). *Dementia Awareness: A Poem*. Unpublished Poem.
- Alfaro-LeFevre, R (2016). *Critical Thinking, Clinical Reasoning, and Clinical Judgment: A Practical Approach, (6th Ed)*. Philadelphia: Saunders-Elsevier
- Allen-Collinson, J. (2012). *Autoethnography: situating personal sporting narratives in socio-cultural contexts*. In *Qualitative Research on Sport and Physical Culture. Research in the Sociology of Sport*. Bingley UK: Emerald Press, ISBN 9781780522968
- Allen-Collinson, J., & Hockey, J. (2008). Autoethnography as 'Valid' Methodology? A Study of Disrupted Identity Narratives. *The International Journal of Interdisciplinary Social Sciences: Annual Review*, 3(6): 209-218. doi:10.18848/1833-1882/cgp/v03i06/52631

Alvesson, M., and Skoldberg, K. (2012). *Reflexive Methodology: New Vistas for Qualitative Research* (2nd ed.). London: Sage.

Alzheimer's Association (2017). *What Is Dementia?* Retrieved from:  
<https://www.alz.org/what-is-dementia.asp>

Alzheimer Europe (2013). *Personhood*. Retrieved from: <https://www.alzheimer-europe.org/Ethics/Definitions-and-approaches/Other-ethical-principles/Personhood>

Alzheimer Europe (2014). *Ethical dilemmas faced by carers and people living with dementia*. Luxemburg: Alzheimer Europe.

Alzheimer Europe (2015). *Ethical dilemmas faced by health and social care professionals providing dementia care in care homes and hospital settings: A guide for use in the context of ongoing professional care training*. Luxemburg: Alzheimer Europe.

Alzheimer's Society (2009). *Counting the cost: Caring for people living with dementia on hospital wards*. London: Alzheimer's Society.

Anderson, L. (2006). Analytic Autoethnography. *Journal of Contemporary Ethnography*, 35 (4): 373-395. doi:10.1177/0891241605280449

Andrew, M. B. & Le Rossignol, R. (2017). Autoethnographic writing inside and outside the academy and ethics. *Writing & Pedagogy*, 9 (2): 225–249.

Retrieved from:

[http://www.drmartinandrew.com/uploads/3/7/1/0/37107517/01-mb\\_andrew\\_and\\_rle\\_rossignol.pdf](http://www.drmartinandrew.com/uploads/3/7/1/0/37107517/01-mb_andrew_and_rle_rossignol.pdf)

Ansell-Pearson, K. (2005). The Reality of the Virtual: Bergson and Deleuze. *MLN*, 120(5), 1112-1127. doi:10.1353/mln.2006.0020

Aspinall, P., Mavros, P., Coyne, R., & Roe, J. (2013). The urban brain: analysing outdoor physical activity with mobile EEG. *British Journal of Sports Medicine*, 49(4), 272-276. doi:10.1136/bjsports-2012-091877

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC Medical Research Methodology*, 8(1). doi:10.1186/1471-2288-8-21

Atkinson, P. (2006). Rescuing Autoethnography. *Journal of Contemporary Ethnography*, 35 (4): 400-404. doi:10.1177/0891241606286980

Atkinson, P. (2015). Rescuing Interactionism from Qualitative Research. *Symbolic Interaction*, 38(4), 467-474. doi:10.1002/symb.183

- Attia, M., & Edge, J. (2017). Be(com)ing a reflexive researcher: a developmental approach to research methodology. *Open Review of Educational Research*, 4 (1): 33-45. doi:10.1080/23265507.2017.1300068
- Austin, W., Goble, E., Leier, B., & Byrne, P. (2009). Compassion Fatigue: The Experience of Nurses. *Ethics and Social Welfare*, 3(2), 195-214.  
doi:10.1080/17496530902951988
- Bandura, A. (2001). Social Cognitive Theory: An Agentic Perspective. *Annual Review of Psychology*, 52 (1): 1-26. doi:10.1146/annurev.psych.52.1.1
- Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action*. London: Institute of Psychiatry, King's College London.
- Bangou, F. (2019). Experimenting with creativity, immigration, language, power, and technology: a research agencement. *Qualitative Research Journal*, 19(2), 82-92. doi:10.1108/qrj-d-18-00015
- Barratt, C. (2017). Exploring how mindfulness and self-compassion can enhance compassionate care. *Nursing Standard*, 31 (21): 55-63.  
doi:10.7748/ns.2017.e10671
- Barry, P. & O'Callaghan, C. (2008). Reflexive Journal Writing: A Tool for Music Therapy Student Clinical Practice Development. *Nordic Journal of Music Therapy*, 17 (1): 55-66. doi:10.1080/08098130809478196.

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology*, 9 (1). doi:10.1186/1471-2288-9-59

Barsuglia, J. P., Nedjat-Haiem, F. R., Shapira, J. S., Velasco, C., Jimenez, E. E., Mather, M. J., & Mendez, M. F. (2014). Observational themes of social behavioral disturbances in frontotemporal dementia. *International Psychogeriatrics*, 1-7. doi:10.1017/s104161021400091x

Barton, S., Findlay, D., & Blake, R. A. (2005). The management of inappropriate vocalisation in dementia: a hierarchical approach. *International Journal of Geriatric Psychiatry*, 20(12), 1180-1186. doi:10.1002/gps.1416

Behar, R. (1996) *The vulnerable observer: Anthropology that breaks your heart*. Boston: Beacon Press.

Belbase, S., Luitel, B. C., & Taylor, P. C. (2013). Autoethnography: A Method of Research and Teaching for Transformative Education. *Journal of Education and Research*, 1, 86-95. doi:10.3126/jer.v1i0.7955

Ben-Shahar, A. R. (2014). *Touching the relational edge: Body psychotherapy*. London: Karnac Books Ltd.

Bergin A. E. (1998). *Religion and mental health: spiritual and religious issues in psychopathology and psychotherapy* (Oskar Pfister Award Lecture). Toronto: Canada.

Bergin, J., & Westwood, R. (2003). The necessities of violence. *Culture and Organization*, 9 (4): 211-223. doi:10.1080/1475955042000195454

Berman, C. W., & Bezkor, M. F. (2010). Transference in Patients and Caregivers. *American Journal of Psychotherapy*, 64(1), 107-114. doi:10.1176/appi.psychotherapy.2010.64.1.107

Bernstein, J. M. (2015). *Torture and dignity: An essay on moral injury*. Chicago: The University of Chicago Press.

Berry, K., & Patti, C. J. (2015). Lost in Narration: Applying Autoethnography. *Journal of Applied Communication Research*, 43(2), 263-268. doi:10.1080/00909882.2015.1019548

Bertrand, E., Landeira-Fernandez, J., & Mograbi, D. C. (2016). Metacognition and Perspective-Taking in Alzheimer's Disease: A Mini-Review. *Frontiers in Psychology*, 7. doi:10.3389/fpsyg.2016.01812

Bewley, T. (2008). *Madness to Mental Illness: A History of the Royal College of Psychiatrists*. Cambridge, England: RCPsych Publications.

- Bickerton, J., Procter, S., Johnson, B. and Medina, A. (2011). Sociophenomenology and conversation analysis: interpreting video lifeworld healthcare interactions. *Nursing Philosophy*, 12 (4): 271-281. doi: 10.1111/j.1466-769X.2011.00506.x
- Bignall, S. (2008). Deleuze and Foucault on desire and power. *Angelaki*, 13(1), 127-147. doi:10.1080/09697250802156125
- Bochner, A. P., & Ellis, C. (2016). *Evocative autoethnography: Writing lives and telling stories*. Walnut Creek, California: Left Coast Press.
- Boersma, M. (2012) A reflection on nurse advocacy for the person experiencing dementia whilst an in-patient in the general and acute sector. *International Practice Development Journal* 2 (1) [1]. Retrieved from: [https://www.fons.org/Resources/Documents/Journal/Vol2No1/IPDJ\\_0201\\_01.pdf](https://www.fons.org/Resources/Documents/Journal/Vol2No1/IPDJ_0201_01.pdf)
- Boole, G. (1854). *An investigation of the laws of thought on which are founded the mathematical theories of logic and probabilities*. Retrieved from: <https://www.gutenberg.org/files/15114/15114-pdf.pdf>
- Boyle, G. (2017). Revealing gendered identity and agency in dementia. *Health & Social Care in the Community*, 25(6), 1787-1793. doi:10.1111/hsc.12452

- Boyle, G., & Warren, L. (2015). Showing how they feel: the emotional reflexivity of people living with dementia. *Families, Relationships and Societies*, 6 (1): 3-19. doi:10.1332/204674315x14328175376100
- Bramley, L., & Matiti, M. (2014). How does it really feel to be in my shoes? Patients' experiences of compassion within nursing care and their perceptions of developing compassionate nurses. *Journal of Clinical Nursing*, 23 (19-20): 2790-2799. doi:10.1111/jocn.12537
- Brannelly, T. (2011). Sustaining citizenship: People living with dementia and the phenomenon of social death. *Nursing Ethics*, 18 (5): 662-671. doi:10.1177/0969733011408049
- Braun, A., Trivedi, D. P., Dickinson, A., Hamilton, L., Goodman, C., Gage, H., ... Manthorpe, J. (2018). Managing behavioural and psychological symptoms in community dwelling older people with dementia: 2. A systematic review of qualitative studies. *Dementia*, 18(7-8), 2950-2970. doi:10.1177/1471301218762856
- Brechin, D, Murphy, G, James, I, Codner, J (2013). *Alternatives to antipsychotic medication: psychological approaches in managing psychological and behavioural distress in people with dementia*. British Psychological Society Publications.

- Brennan, J. (2018). Recognition and personhood: A critique of Bernstein's account of the wrongfulness of torture. *European Journal of Philosophy*, 27 (1): 211-226.  
doi:10.1111/ejop.12370
- Brim, V. (2014) Using the Concepts of Transference and Counter-transference in Care Management Supervision. *The Journal of Aging Life Care*. Retrieved from:  
<https://www.aginglifecarejournal.org/using-the-concepts-of-transference-and-counter-transference-in-care-management-supervision/>
- Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy*, 7 (4): 209-215.  
doi:10.1258/135581902320432732
- Brockmeier, J., & Carbaugh, D. A. (2001). *Narrative and Identity: Studies in Autobiography, Self and Culture*. Amsterdam, Netherlands: John Benjamin's Publishing.
- Buber, M. (1970). *I and Thou*. New York: Charles Scribner's Sons.
- Buhr, G. T., & White, H. K. (2007). Difficult Behaviors in Long-term Care Patients with Dementia. *Journal of the American Medical Directors Association*, 8 (3): e101-e113. doi:10.1016/j.jamda.2006.12.012

- Campbell, E. (2017). "Apparently Being a Self-Obsessed C\*\*t Is Now Academically Lauded": Experiencing Twitter Trolling of Autoethnographers. *Forum: Qualitative Social Research*, 18 (3): Art. 16. Retrieved from: <http://dx.doi.org/10.17169/fqs-18.3.2819>.
- Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R. ... Donovan, J. (2011). Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technology Assessment*, 15(43). doi:10.3310/hta15430
- Carey, M. C., Kent, B., & Latour, J. M. (2019). Using meta-ethnography to develop a conceptual model of peer-assisted learning of nursing students in clinical practice. *Nursing Open*, 6(2), 473-481. doi:10.1002/nop2.229
- CASP (2018). *Critical Appraisal Skills Programme (CASP Qualitative Checklist)*. Retrieved from: <https://casp-uk.net/casp-tools-checklists/>
- Cerami, C., & Cappa, S. F. (2013). The behavioral variant of frontotemporal dementia: linking neuropathology to social cognition. *Neurological Sciences*, 34 (8): 1267-1274. doi:10.1007/s10072-013-1317-9
- Chaney, S. (2010). Behaviour. *The Lancet*, 376(9756), 1893. doi:10.1016/s0140-6736(10)62202-7

- Chang, H. (2007). Autoethnography: Raising Cultural Consciousness of Self and Others. *Methodological Developments in Ethnography*, 207-221.  
doi:10.1016/s1529-210x(06)12012-4
- Chang, H. (2008). *Autoethnography as method*. Walnut Creek, CA: Left Coast Press.
- Chang, H. (2016). Autoethnography in Health Research. *Qualitative Health Research*, 26 (4): 443-451. doi:10.1177/1049732315627432
- Chowdhry, S. (2010). Exploring the concept of empathy in nursing: can it lead to abuse of patient trust? *Nursing Times*; 106: 42, 22-25.
- Clark, A. J. (2014). *Empathy in Counselling and Psychotherapy: Perspectives and Practices*. London, England: Routledge.
- Clarke, A., Jane Hanson, E., & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, 12(5), 697-706. doi:10.1046/j.1365-2702.2003.00784.x
- Clissett, P., Porock, D., Harwood, R. H., & Gladman, J. R. (2013). The challenges of achieving person-centred care in acute hospitals: A qualitative study of people living with dementia and their families. *International Journal of Nursing Studies*, 50 (11): 1495-1503. doi:10.1016/j.ijnurstu.2013.03.001

Cockayne, D. G., Ruez, D., & Secor, A. (2016). Between ontology and representation. *Progress in Human Geography*, 41(5), 580-599.

doi:10.1177/0309132516650028

Cohen, D. J., & Crabtree, B. F. (2008). Evaluative Criteria for Qualitative Research in Health Care: Controversies and Recommendations. *The Annals of Family*

*Medicine*, 6 (4): 331-339. doi:10.1370/afm.818

Cole, D. R., & Masny, D. (2012). Education and the politics of becoming. *Discourse: Studies in the Cultural Politics of Education*, 33(1), 1-3.

doi:10.1080/01596306.2012.632156

Coleman A.E., Snarey J. (2011). *James-Lange Theory of Emotion*. In: Goldstein S., Naglieri J.A. (eds) *Encyclopaedia of Child Behavior and Development*.

Springer, Boston, MA

Collerton, D., & Taylor, J. (2013). Advances in the treatment of visual hallucinations in neurodegenerative diseases. *Future Neurology*, 8(4), 433-444.

doi:10.2217/fnl.13.19

Collins English Dictionary (2019). *Definition of in medias res*. Retrieved from:

<https://www.collinsdictionary.com/dictionary/english/in-medias-res>

- Combs, B., & Cox, A. (2017). Update on the treatment of Parkinson's disease psychosis: role of pimavanserin. *Neuropsychiatric Disease and Treatment*, 13, 737-744. doi:10.2147/ndt.s108948
- Congress of Qualitative Inquiry. (2007). *Position statement on qualitative research on IRBs*. University of Illinois at Urbana-Champaign, USA, 4-6 May 2007. Retrieved from: <http://icqi.org/wp-content/uploads/2013/02/QI2007.pdf>
- Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO. *Qualitative Health Research*, 22(10), 1435-1443. doi:10.1177/1049732312452938
- Corbett, A., Burns, A., & Ballard, C. (2012). Management of behavioural and psychological symptoms of dementia: Development of a best practice guide. *Alzheimer's & Dementia*, 8(4), P609. doi:10.1016/j.jalz.2012.05.1632
- Corry, M., Porter, S., & McKenna, H. (2018). The redundancy of positivism as a paradigm for nursing research. *Nursing Philosophy*, 20(1), e12230. doi:10.1111/nup.12230
- Cotelli, M., Adenzato, M., Cantoni, V., Manenti, R., Alberici, A., Enrici, I., Borroni, B. (2018). Enhancing theory of mind in behavioural variant frontotemporal dementia with transcranial direct current stimulation. *Cognitive, Affective, & Behavioral Neuroscience*. doi:10.3758/s13415-018-0622-4

Covey, S. R. (2004). *The 7 Habits of Highly Effective People: Powerful Lessons in Personal Change*. New York, NY: Simon & Schuster.

Currie, M. (2013). *The Unexpected: Narrative Temporality and the Philosophy of Surprise*. Edinburgh: Edinburgh University Press. Retrieved from <http://www.jstor.org/sTable/10.3366/j.ctt3fgrm7>

Dashper, K. (2015). Revise, resubmit and reveal? An autoethnographer's story of facing the challenges of revealing the self through publication. *Current Sociology*, 63 (4): 511-527. doi:10.1177/0011392115583879

Dashper, K. (2016). Researching from the Inside: Autoethnography and Critical Event Studies. *Critical Event Studies*, 213-229. doi:10.1057/978-1-137-52386-0\_11

Decety, J., & Lamm, C. (2009). *Empathy and Intersubjectivity*. In Berntson, G. G., & Cacioppo, J. T. (eds.) (2009). *Handbook of neuroscience for the behavioral sciences (2<sup>nd</sup> ed)*. Hoboken, N.J: J. Wiley.

De Jaegher, H., Pieper, B., Clénin, D., & Fuchs, T. (2016). Grasping intersubjectivity: an invitation to embody social interaction research. *Phenomenology and the Cognitive Sciences*, 16(3), 491-523. doi:10.1007/s11097-016-9469-8

- Delamont, S. (2007). 'Arguments against autoethnography', *Qualitative Researcher*, 4, 2-4. Retrieved from:  
[http://www.cardiff.ac.uk/socsi/qualiti/QualitativeResearcher/QR\\_Issue4\\_Feb07.p](http://www.cardiff.ac.uk/socsi/qualiti/QualitativeResearcher/QR_Issue4_Feb07.p)
- Delamont, S. (2009). The only honest thing: autoethnography, reflexivity and small crises in fieldwork. *Ethnography and Education*, 4(1), 51-63.  
doi:10.1080/17457820802703507
- Deleuze, G. (1984). *Seminars on Cinema*, Paris: University of Paris 8–Vincennes-St. Denis. Retrieved from: <http://www2.univ-paris8.fr/deleuze/>
- Deleuze, G. (1988). *Bergsonism*. New York: Zone Books.
- Deleuze, G. (1989). *Cinema 2: The Time-Image*. (Tomlinson, H & Galeta, R Trans). London, England: Burns & Oates.
- Deleuze, G. (1993). *The fold: Leibniz and the baroque*. (Conley, T. Trans). Minneapolis: University of Minnesota Press.
- Deleuze, G. (1994). *Difference and Repetition*. (Patton, P. Trans). New York: Columbia University Press.
- Deleuze, G. (2001). *Pure immanence: Essays on a life*. (Boyman, A. Trans). New York: Zone Books.

- Deleuze, G., and Guattari, F. (1987). *Thousand Plateaus: Capitalism and schizophrenia*. (Massumi, B. Trans). Minneapolis, MN: University of Minnesota Press.
- Denshire, S. (2013). 'Autoethnography', Sociopedia.isa, doi: 10.1177/205684601351
- Denshire, S. (2014). On auto-ethnography. *Current Sociology*, 62 (6): 831-850.  
doi:10.1177/0011392114533339
- Denshire, S., & Lee, A. (2013). Conceptualizing Autoethnography as Assemblage: Accounts of Occupational Therapy Practice. *International Journal of Qualitative Methods*, 12 (1): 221-236. doi:10.1177/160940691301200110
- Denzin, N. K. (2006). Analytic Autoethnography, or Déjà Vu all Over Again. *Journal of Contemporary Ethnography*, 35 (4): 419-428.  
doi:10.1177/0891241606286985
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research*. London: Sage.
- Department for Constitutional Affairs (2007). *The Mental Capacity Act 2005 Code of Practice*. United Kingdom: Crown Copyright.

- Department of Health (DH) (2010). *'Nothing ventured, nothing gained': Risk guidance for people living with dementia*. London: DH
- Department of Health (DH) (2012). *Compassion in practice; Nursing, Midwifery and Care Staff; Our Vision and Strategy*. London; DH
- DeVault, C. (2013). *Joyce's love stories*. Farnham: Ashgate.
- Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2009). Researching sensitive topics: qualitative research as emotion work. *Qualitative Research*, 9(1), 61-79. doi:10.1177/1468794108098031
- Digby, R. L., Lee, S. F., & Williams, A. (2016). *Nurse empathy and the care of people living with dementia*. *The Australian Journal of Advanced Nursing*, 34(1), 52-59.
- Dimitrova, N. (2003). Multimedia Content Analysis: The Next Wave. *Lecture Notes in Computer Science*, 9-18. doi:10.1007/3-540-45113-7\_2
- Di Paolo E. A. and De Jaegher, H. (2015). Toward an embodied science of intersubjectivity: widening the scope of social understanding research. *Frontiers in Psychology*. 6:234. doi: 10.3389/fpsyg.2015.00234
- Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a

quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy*, 12 (1): 42-47. doi:10.1258/135581907779497486

Doloriert, C., & Sambrook, S. (2009). Ethical confessions of the “I” of autoethnography: the student's dilemma. *Qualitative Research in Organizations and Management: An International Journal*, 4 (1): 27-45. doi:10.1108/17465640910951435

Donovan, N. (2011). *Us and them: seeking the autoethnographic ‘we’*. In Scott, D., Carron J. M. C., Mandere, M., Warwick, R. and Appiah, S. (eds.). *Creative Connections: Exploring and Discovering Relationships*. Nottingham: Nottingham Trent University, pp. 40-45. ISBN 9781842331453

Douglas, K. & Carless, D. (2013) *A History of Autoethnographic Inquiry* in Holman Jones, S., Adams, T. E., & Ellis, C. (eds), *Handbook of Autoethnography*. Walnut Creek, CA: Left Coast Press, p. 84-106.

Draper, B.M. & Wand, A. (2015). *Behavioural and Psychological Symptoms of Dementia*. In Pachana N (ed.). *Encyclopedia of Geropsychology*. Springer. [http://dx.doi.org/10.1007/978-981-287-080-3\\_88-1](http://dx.doi.org/10.1007/978-981-287-080-3_88-1)

Dronsfield, J. (2012). Deleuze and the image of thought. *Philosophy Today*, 56 (4): 404 – 414.

- Drozdzewski, D. (2015). Retrospective reflexivity: The residual and subliminal repercussions of researching war. *Emotion, Space and Society*, 17: 30-36.  
doi:10.1016/j.emospa.2015.03.004
- Duncan, M. (2004). Autoethnography: Critical Appreciation of an Emerging Art. *International Journal of Qualitative Methods*, 3 (4): 28-39.  
doi:10.1177/160940690400300403
- Dupuis, S. L., Wiersma, E., & Loiselle, L. (2012). Pathologizing behavior: Meanings of behaviors in dementia care. *Journal of Aging Studies*, 26 (2): 162-173.  
doi:10.1016/j.jaging.2011.12.001
- Dwyer, M., & Byrne, G. J. (2000). Disruptive Vocalization and Depression in Older Nursing Home Residents. *International Psychogeriatrics*, 12(4), 463-471.  
doi:10.1017/s104161020000658x
- Edberg, A., Bird, M., Richards, D. A., Woods, R., Keeley, P., & Davis-Quarrell, V. (2008). Strain in nursing care of people with dementia: Nurses' experience in Australia, Sweden and United Kingdom. *Aging & Mental Health*, 12(2), 236-243. doi:10.1080/13607860701616374
- Edwards, S. (2017). Reflecting differently. New dimensions: reflection-before-action and reflection-beyond-action. *International Practice Development Journal*, 7 (1): 1-14. doi:10.19043/ipdj.71.002

- Eichbaum, Q. (2014). Thinking about Thinking and Emotion: The Metacognitive Approach to the Medical Humanities that Integrates the Humanities with the Basic and Clinical Sciences. *The Permanente Journal*. 18 (4): 64-75.  
doi:10.7812/tpp/14-027
- Ellingson, L. L. (2008). *Engaging Crystallization in Qualitative Research: An Introduction*. Thousand Oaks, CA: SAGE Publications.
- Ellingson, L. L., & Ellis, C. (2008). *Autoethnography as constructionist project*. In Holstein, J. A., & Gubrium, J. F. (eds.), *Handbook of constructionist research* (pp. 445-466). New York: Guilford Press.
- Ellis, C. (1993). 'There are Survivors': Telling A Story of Sudden Death. *The Sociological Quarterly*, 34 (4): 711-730. doi:10.1111/j.1533-8525.1993.tb00114.x
- Ellis, C. (1995). 'Emotional and Ethical Quagmires in Returning to the Field.' *Journal of Contemporary Ethnography*, 24 (1): 68-98.  
doi:10.1177/089124195024001003
- Ellis, C. (1999). Heartful Autoethnography. *Qualitative Health Research*, 9(5), 669-683. doi:10.1177/104973299129122153
- Ellis, C. (2000). Creating criteria: An ethnographic short story. *Qualitative Inquiry*, 6 (2), 273-277.

- Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. Walnut Creek: AltaMira Press.
- Ellis, C. (2007). Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry*, 13, 3-29. doi:10.1177/1077800406294947
- Ellis, C., Adams, T., & Bochner, A. P. (2011). Autoethnography: An Overview. Forum: *Qualitative Social Research*, 12 (1): 35–43. Retrieved from: <http://nbn-resolving.de/urn:nbn:de:0114-fqs1101108>
- Ellis, C. & Bochner, A. P. (2000). Autoethnography, personal narrative, and personal reflexivity. In: Denzin, N. & Lincoln, Y., 2000. *Handbook of qualitative research*. 2<sup>nd</sup> ed. Thousand Oaks, CA: Sage, 733-768.
- Ellis, M., & Astell, A. (2017). Communicating with people living with dementia who are nonverbal: The creation of Adaptive Interaction. *PloS one*, 12 (8), e0180395. doi:10.1371/journal.pone.0180395
- Elsden, L. (2016). Can compassion be taught? *British Journal of Community Nursing*, 21(5), 221-221. doi:10.12968/bjcn.2016.21.5.221
- England, S. E. (2016). Private Troubles, Master Narratives: Dilemmas of Dementia Care in a Short Story. *The Gerontologist*, (57) 5 963–968  
doi:10.1093/geront/gnw086

- Ericsson, I., Kjellström, S., & Hellström, I. (2011). Creating relationships with persons with moderate to severe dementia. *Dementia*, 12(1), 63-79.  
doi:10.1177/1471301211418161
- Ervin, K., Cross, M., & Koschel, A. (2014). Barriers to managing Behavioural and Psychological Symptoms of Dementia: Staff perceptions. *Collegian*, 21 (3): 201-207. doi:10.1016/j.colegn.2013.04.002
- Eslinger, P. J. (2005). Metacognitive deficits in frontotemporal dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, 76 (12): 1630-1635.  
doi:10.1136/jnnp.2004.053157
- Etherington, K. (2004). *Becoming a Reflexive Researcher - Using Our Selves in Research*. London, England: Jessica Kingsley Publishers.
- Fabian, J. (2014). Ethnography and intersubjectivity. *HAU: Journal of Ethnographic Theory*, 4 (1): 199-209. doi:10.14318/hau4.1.008
- Fairclough, H. R. (1961). *Horace: Satires, Epistles and Ars Poetica*. Cambridge, Massachusetts: Harvard University Press.
- Farrell, L., Bourgeois-Law, G., Regehr, G., & Ajjawi, R. (2015). Autoethnography: introducing 'I' into medical education research. *Medical Education*, 49 (10): 974-982. doi:10.1111/medu.12761

- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The Fundamentals of Person-Centered Care for Individuals with Dementia. *The Gerontologist*, 58(suppl\_1), S10-S19. doi:10.1093/geront/gnx122
- Feast, A., Orrell, M., Charlesworth, G., Poland, F., Featherstone, K., Melunsky, N., & Moniz-Cook, E. (2018). *Using Meta-Ethnography to Synthesize Relevant Studies: Capturing the Bigger Picture in Dementia with Challenging Behavior Within Families*. SAGE Research Methods Cases Part 2. London: Sage doi: <https://dx.doi.org/10.4135/9781526472427>
- Ferdinand, J., Pearson, G., Rowe, M., & Worthington, F. (2007). A different kind of ethics. *Ethnography*, 8 (4): 519-543. doi:10.1177/1466138107083566
- Fernandez-Duque, D. and Black, S. E. (2007). Metacognitive judgment and denial of deficit: Evidence from frontotemporal dementia. *Judgment Decision Making*, 2 (5): 359-370.
- Fernandez-Martinez, M., Molano, A., Castro, J., & Zarranz, J. J. (2010). Prevalence of Neuropsychiatric Symptoms in Mild Cognitive Impairment and Alzheimer's Disease, and its Relationship with Cognitive Impairment. *Current Alzheimer Research*, 999 (999): 1-10. doi:10.2174/1567210204558622050
- Ferrari, R. (2015). Writing narrative style literature reviews. *Medical Writing*, 24(4), 230-235. doi:10.1179/2047480615z.000000000329

Flesner, M. K., & Rantz, M. J. (2004). Mutual Empowerment and Respect. *Journal of Nursing Care Quality*, 19 (3): 193-196. doi:10.1097/00001786-200407000-00004

Forrester, M. (2012) *Doing qualitative research in psychology: a practical guide*. London: Sage.

Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R., & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ*, 332(7544), 756-761. doi:10.1136/bmj.38782.575868.7c

Foster, K., McCloughen, A., Delgado, C., Kefalas, C., & Harkness, E. (2015). Emotional intelligence education in pre-registration nursing programmes: An integrative review. *Nurse Education Today*, 35(3), 510-517. doi:10.1016/j.nedt.2014.11.009

Fournier, M. (2014). Lines of Flight. *Transgender Studies Quarterly*, 1 (1-2): 121–122. doi: 10.1215/23289252-2399785

Fox, N.J. (2012) Deleuze and Guattari. In: Scambler, G. (ed.) *Contemporary Theorists for Medical Sociology*. London: Routledge, p. 150-166.

France, E. F., Cunningham, M., Ring, N., Uny, I., Duncan, E. A., Jepson, R. G., ...

Noyes, J. (2019). Improving reporting of meta-ethnography: the eMERGE reporting guidance. *BMC Medical Research Methodology*, 19(1).

doi:10.1186/s12874-018-0600-0

Frank, A. W. (2016). Truth telling, companionship, and witness: An agenda for narrative ethics. *Hastings Center Report*, 46 (3): 17-21. doi:10.1002/hast.591

Freeman, M. (1997). Death, narrative integrity, and the radical challenge of self understanding: A reading of Tolstoy's Death of Ivan Ilych. *Ageing and Society*, 17 (4): 373–398. <https://doi.org/10.1017/S0144686X97006508>

Freud, S. (1997). *Dora: An Analysis of a Case of Hysteria* (Rieff, P. Trans) New York, NY: Simon & Schuster.

Fukada, M. (2018) Nursing competency: definition, structure and development. *Yonago Acta Medica*. 61(1):1-7.

Fullbrook, E. (2004). *Descartes Legacy: Intersubjective Reality, Intrasubjective Theory*. In Davis, J. B., Marciano, A., & Runde, J. (eds.) (2004). *The Elgar companion to economics and philosophy* (pp403-422). Cheltenham, UK: Edward Elgar.

Fusch, P. I., & Ness, L. R. (2015). Are We There Yet? Data Saturation in Qualitative Research. *The Qualitative Report*, 20 (9): 1408-1416. Retrieved from: <http://nsuworks.nova.edu/tqr/vol20/iss9/3>

Gallagher, P., Curtin, D., De Siún, A., O'Shea, E., Kennelly, S., O'Neill, D., & Timmons, S. (2016). Antipsychotic prescription amongst hospitalized patients with dementia. *QJM*, 109 (9): 589-593. doi:10.1093/qjmed/hcw023

Gallese, V. (2001). "The 'Shared manifold' hypothesis: From Mirror Neurons to Empathy." *Journal of Consciousness Studies*. (8): 5-7, 33-50.

Gariglio, L. (2018). Doing (Prison) Research Differently: Reflections on Autoethnography and 'Emotional Recall'. *Oñati Socio-legal Series*, 8(2), 205-224. doi:10.35295/osls.iisl/0000-0000-0000-0932

Gentle Teaching Foundation (nd) *Gentle teaching*. Netherlands: Gentle Teaching Foundation Retrieved from: <https://gentleteaching.nl/gentle/en/wat-is-en/sum>

Gill, D., Almutairi, S., & Donyai, P. (2017). "The Lesser of Two Evils" Versus "Medicines not Smarties": Constructing Antipsychotics in Dementia. *The Gerontologist*, 59(3), 570-579. doi:10.1093/geront/gnx178

Glocer fiorini, L. (2016). Intersubjectivity, otherness, and thirdness: A necessary relationship, *The International Journal of Psychoanalysis*, 97: 4, 1095-1104, DOI: 10.1111/1745-8315.12432

- Goethals, S., Gastmans, C., & De Casterlé, B. D. (2010). Nurses' ethical reasoning and behaviour: A literature review. *International Journal of Nursing Studies*, 47(5), 635-650. doi:10.1016/j.ijnurstu.2009.12.010
- Goodman, C. (2011). The organisational culture of nursing staff providing long-term dementia care is related to quality of care. *Evidence-Based Nursing*, 14(3), 88-89. doi:10.1136/ebn1158
- Grant, C. (2009). *Letting it go: An autoethnographic account of a musician's loss*. In Ellis, C. & Bartleet, B., *Musical autoethnography: Creative explorations of the self through music*, pp.121-135. Bowen Hills: Australian Academic Press.
- Grattan-Guinness, I. (2005). *Landmark Writings in Western Mathematics 1640-1940*. Amsterdam, Netherlands: Elsevier.
- Gray, D. E. (2014). *Doing Research in the Real World*. Los Angeles, California: SAGE.
- Greer, J. (2016). *Resilience and Personal Effectiveness for Social Workers*. London: Sage.
- Grellier, J. (2013). Rhizomatic mapping: spaces for learning in higher education. *Higher Education Research & Development*, 32(1), 83-95. doi:10.1080/07294360.2012.750280

- Gridley, K., Brooks, J., Birks, Y., Baxter, K., & Parker, G. (2016). Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care. *Health Services and Delivery Research, 4*(23), 1-298. doi:10.3310/hsdr04230
- Grist, H. (2013) *The Dennis Potter Heritage Project: Auto/Ethnography as Process and Product*. eSharp, 20. pp. 1-25. Retrieved from:  
<http://eprints.glos.ac.uk/2006/>
- Hallett, N. (2018). Preventing and managing behaviours that challenge. *Nursing Standard, 32* (26), 51-63. doi:10.7748/ns.2018.e10969
- Haley, B., Heo, S., Wright, P., Barone, C., Rao Rettiganti, M., & Anders, M. (2017). Relationships among active listening, self-awareness, empathy, and patient-centered care in associate and baccalaureate degree nursing students. *NursingPlus Open, 3*: 11-16. doi:10.1016/j.npls.2017.05.001
- Hamdy, R. C., Kinser, A., Lewis, J. V., Copeland, R., Depelteau, A., Kendall-Wilson, T., & Whalen, K. (2017). Hallucinations Are Real to Patients With Dementia. *Gerontology and Geriatric Medicine, 3*, 233372141772110. doi:10.1177/2333721417721108
- Hampson, C., & Morris, K. (2016). Dementia: Sustaining Self in the Face of Cognitive Decline. *Geriatrics, 1*(4), 25. doi:10.3390/geriatrics1040025

- Hanjalic, A., Sebe, N., & Chang, E. (2006). Multimedia content analysis, management and retrieval: trends and challenges. *Multimedia Content Analysis, Management, and Retrieval 2006*. doi:10.1117/12.673788
- Hansen, A., Hauge, S., & Bergland, Å. (2017). Meeting psychosocial needs for persons with dementia in home care services – a qualitative study of different perceptions and practices among health care providers. *BMC Geriatrics, 17*(1). doi:10.1186/s12877-017-0612-3
- Hanson, B. (2015). Objectivities: social constructivist roots of positivism. *Quality & Quantity, 49* (2): 857-865. doi:10.1007/s11135-014-0027-6
- Harrison, J. K., Reid, J., Quinn, T. J., & Shenkin, S. D. (2016). Using quality assessment tools to critically appraise ageing research: a guide for clinicians. *Age and ageing, 46* (3), 359-365. doi:10.1093/ageing/afw223
- Harwood, R. (2017). How to deal with violent and aggressive patients in acute medical settings. *Journal of the Royal College of Physicians of Edinburgh, 47* (2), 176-182. Doi:10.4997/jrcpe.2017.218
- Health Education England (HEE) (2018) Dementia Training Standards Framework. Health Education England: Leeds. Retrieved from: <https://www.hee.nhs.uk/our-work/dementia-awareness/core-skills>

- Hein, S. F. (2018). Deleuze, Immanence, and Immanent Writing in Qualitative Inquiry: Nonlinear Texts and Being a Traitor to Writing. *Qualitative Inquiry*, 25(1), 83-90. doi:10.1177/1077800418784328
- Henderson, *Gender and class in English asylums, 1890-1914*. Basingstoke: Palgrave Macmillan.
- Hesse-Biber, S. N. (2007). *Handbook of feminist research: Theory and praxis*. Thousand Oaks, CA: Sage Publications Inc.
- Hide, L. (2014). Heider, K. G. (1988) The Rashoman effect: when ethnographers disagree. *American Anthropologist*, 90 (1):73-81. Retrieved from: <http://polaris.gseis.ucla.edu/gleazer/291B/Heider-Rashomon.pdf>
- Higgs, P., & Gilleard, C. (2016). Interrogating personhood. *Personhood, Identity and Care in Advanced Old Age*. doi:10.1332/policypress/9781447319054.003.0002
- Hirschi, T. (1969). *The causes of delinquency*. Berkeley: The University of California Press.
- Hirschi, T. (1977). Causes and prevention of juvenile delinquency. *Sociological Inquiry*, 47: 322-34. Doi.org/10.1111/j.1475-682X.1977.tb00804.x
- Hoffman, M. L. (2001). *Empathy and Moral Development: Implications for Caring and Justice*. Cambridge, England: Cambridge University Press.

Hofmeyer, A., Toffoli, L., Vernon, R., Taylor, R., Fontaine, D., Klopper, H. C., & Coetzee, S. K. (2016). Teaching The Practice Of Compassion To Nursing Students Within An Online Learning Environment: A Qualitative Study Protocol. *Contemporary Issues in Education Research (CIER)*, 9(4), 201. doi:10.19030/cier.v9i4.9790

Holt, N. L. (2003). Representation, Legitimation, and Autoethnography: An Autoethnographic Writing Story. *International Journal of Qualitative Methods*, 2 (1): 18-28. doi:10.1177/160940690300200102

Honan, E and Sellers, M (2006). 'So how does it work? – rhizomatic methodologies.' In Jeffery, P. L (ed.) *AARE Education Research Conference*, Adelaide, 27-30 November 2006, pp. 1-9. Retrieved from: <http://researchbank.rmit.edu.au/view/rmit:18896>

Horning, S. M., Melrose, R., & Sultzer, D. (2013). Insight in Alzheimer's disease and its relation to psychiatric and 173heffield173l disturbances. *International Journal of Geriatric Psychiatry*, 29 (1): 77-84. Doi:10.1002/gps.3972

Horton-Deutsch, S., & Sherwood, G. (2008). Reflection: an educational strategy to develop emotionally-competent nurse leaders. *Journal of Nursing Management*, 16(8), 946-954. doi:10.1111/j.1365-2834.2008.00957.x

- Hossain, F.M.A. & Ali, M.D.K. (2014). Relation between Individual and Society. *Open Journal of Social Sciences*, 2: 130-137. doi.org/10.4236/jss.2014.28019
- Hughes, J. C. (2014). *How We Think about Dementia: Personhood, Rights, Ethics, the Arts and what They Mean for Care*. London, England: Jessica Kingsley Pub.
- Hughes, R. G. (Ed.). (2008). *Patient safety and quality: An evidence-based handbook for nurses (AHRQ Publication No. 08-0043)*. Agency for Healthcare Research and Quality. Retrieved from: <https://www.ncbi.nlm.nih.gov/books/NBK2643/>
- Hung, L., Phinney, A., Chaudhury, H., Rodney, P., Tabamo, J., & Bohl, D. (2017). “Little things matter!” Exploring the perspectives of patients with dementia about the hospital environment. *International Journal of Older People Nursing*, 12 (3): e12153. Doi:10.1111/opn.12153
- Husserl, E. (1982). *Cartesian Meditations*, 7<sup>th</sup> Impression (Cairns, D, Trans.) Netherlands: Martinus Nijhoff Publishers. Retrieved from: Kluwer <http://www.ict.griffith.edu.au/~johnt/PC/HusserlFirstCartesianMeditation.pdf>
- Ibañez, A., & Manes, F. (2012). Contextual social cognition and the behavioral variant of frontotemporal dementia. *Neurology*, 78 (17): 1354-1362. Doi:10.1212/wnl.0b013e3182518375

Ijaopo, E. O. (2017). Dementia-related agitation: a review of non-pharmacological interventions and analysis of risks and benefits of pharmacotherapy. *Translational Psychiatry*, 7 (10): e1250.

Doi:10.1038/tp.2017.199

Jack, K. (2012). “Putting the words ‘I am sad’, just doesn't quite cut it sometimes!”: The use of art to promote emotional awareness in nursing students. *Nurse Education Today*, 32(7), 811-816. doi:10.1016/j.nedt.2012.04.020

Jackson, A., & Mazzei L. (2008). Experience and ‘I’ in autoethnography. A deconstruction. *International Review of Qualitative Research*, 1 (3): 299–318.

Jackson, S., Backett-Milburn, K., & Newall, E. (2013). Researching Distressing Topics. Reflexivity and Emotional Labor in the Secondary Analysis of Children and Young People’s Narratives of Abuse. *SAGE Open*, 3 (2): 215824401349070. doi:10.1177/2158244013490705

Jago, B. (2002). ‘Chronicling an academic depression’ *Journal of Contemporary Ethnography*, 31: 729-756. Doi:0.1177/ 089124102237823

James, W. (1884). What is an emotion? *Mind*, 9: 188–205. Retrieved from: <https://academic.oup.com/mind/article/os-IX/34/188/2870785>

- Jeffrey, D. (2016). Empathy, sympathy and compassion in healthcare: Is there a problem? Is there a difference? Does it matter? *Journal of the Royal Society of Medicine*, 109 (12): 446-452. doi:10.1177/0141076816680120
- Johnson, E. K. (2015). The business of care: the moral labour of care workers. *Sociology of Health & Illness*, 37 (1): 112-126. Doi:10.1111/1467-9566.12184
- Johnson, H. F. (2016). Exploring the Lived Experience of People living with dementia through Interpretative Phenomenological Analysis. *The Qualitative Report*, 21 (4): 695-711. Retrieved from: <http://nsuworks.nova.edu/tqr/vol21/iss4/7>
- Johnston, D., & Strong, T. (2008). Reconciling Voices in Writing an Autoethnographic Thesis. *International Journal of Qualitative Methods*, 7(3), 47-61. doi:10.1177/160940690800700304
- Jootun, D., & McGhee, G. (2011). Effective communication with people who have dementia. *Nursing Standard*, 25(25), 40-46. doi:10.7748/ns2011.02.25.25.40.c8347
- Josephsen, J. (2014). Critically Reflexive Theory: A Proposal for Nursing Education. *Advances in Nursing*, 2014, 1-7. doi:10.1155/2014/594360
- Kadri, A., Rapaport, P., Livingston, G., Cooper, C., Robertson, S., & Higgs, P. (2018). Care workers, the unacknowledged persons in person-centred care: A

secondary qualitative analysis of UK care home staff interviews. *PloS ONE*,  
13 (7): . doi:10.1371/journal.pone.0200031

Kaiser, P., & Eley, R. (2016). *Life Story Work with People with Dementia: Ordinary Lives, Extraordinary People*. London, England: Jessica Kingsley Publishers.

Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2015). Assessment and management of behavioral and psychological symptoms of dementia. *BMJ*, 350 (mar02 7): h369-h369. Doi:10.1136/bmj.h369

Kalis, A., Schermer, M. H., & Van Delden, J. J. (2005). Ideals Regarding a Good Life for Nursing Home Residents with Dementia: views of professional caregivers. *Nursing Ethics*, 12 (1): 30-42. doi:10.1191/0969733005ne756oa

Karnieli-Miller, O., Strier, R., & Pessach, L. (2008). Power Relations in Qualitative Research. *Qualitative Health Research*, 19(2), 279-289.  
doi:10.1177/1049732308329306

Kelly, A. (2008). Forgetting and the memory of forgetting. *Dementia*, 7 (4): 451-460.  
doi:10.1177/1471301208096629

Kelley, A. (2014). Layers of Consciousness: An Autoethnographic Study of the Comprehensive Exam Process. *International Journal of Doctoral Studies*, 9: 347 – 360. Doi:10.28945/2079

- Kelton, M. F. (2014). Clinical Coaching – An innovative role to improve marginal nursing students’ clinical practice. *Nurse Education in Practice*, 14(6), 709-713. Doi:10.1016/j.nepr.2014.06.010
- Kerasidou, A. (2019). Empathy and Efficiency in Healthcare at Times of Austerity. *Health Care Analysis*, 27(3), 171-184. doi:10.1007/s10728-019-00373-x
- Kimura, H., Tamoto, T., Kanzaki, N., & Shinchi, K. (2011). Burnout and Characteristics of Mental Health of Caregivers of Elderly Dementia Patients. *Journal of Rural Medicine*, 6(2), 47-53. Doi:10.2185/jrm.6.47
- Kindell, J., Burrow, S., Wilkinson, R., & Keady, D. J. (2014). Life story resources in dementia care: a review. *Quality in Ageing and Older Adults*, 15(3), 151-161. doi:10.1108/qaqa-02-2014-0003
- King, R. & O'Brien, T. (2011). Transference and countertransference: Opportunities and risks as two technical constructs migrate beyond their psychoanalytic homeland. *Psychotherapy in Australia*, 17(4), pp. 12-17. Retrieved from: [https://www.psychotherapy.com.au/fileadmin/site\\_files/pdfs/Transference\\_and\\_Countertransference.pdf](https://www.psychotherapy.com.au/fileadmin/site_files/pdfs/Transference_and_Countertransference.pdf)
- Kitwood, T. (1990). The Dialectics of Dementia: With Particular Reference to Alzheimer’s Disease. *Ageing and Society*, 10 (02): 177-196. Doi:10.1017/s0144686x00008060

- Kitwood T. (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.
- Kitwood, T. (1997a). The experience of dementia. *Aging & Mental Health*, 1 (1): 13-22. Doi:10.1080/13607869757344
- Kortenaar, P. (2013). *A Rhizoanalysis of the Ontario Science Centre Science School's Innovation Project: A Case Study*. (PhD Dissertation). Project of the Ontario Science Centre Science School. USA.
- Koshy, K., Limb, C., Gundogan, B., Whitehurst, K., & Jafree, D. J. (2017). Reflective practice in health care and how to reflect effectively. *International Journal of Surgery Oncology*, 2(6), e20. doi:10.1097/ij9.0000000000000020
- Krueger, J. (2013). *The space between us: Embodiment and intersubjectivity in Watsuji and Levinas*. In L. Kalmanson, F. Garrett & S Mattice (eds.), *Levinas and Asian Thought*. Pittsburgh: Duquesne University Press.
- Kudo, T. (2016). Basic Theory of Pharmacology for Alzheimer's Disease. *Practical Pharmacology for Alzheimer's Disease*, 1-25. doi:10.1007/978-3-319-26206-2\_1
- Kuiper, R. A., & Pesut, D. J. (2004). Promoting cognitive and metacognitive reflective reasoning skills in nursing practice: self-regulated learning theory. *Journal of Advanced Nursing*, 45 (4): 381-391. doi:10.1046/j.1365-2648.2003.02921.x

Lachal, J., Revah-Levy, A., Orri, M., & Moro, M. R. (2017). Metasynthesis: An Original Method to Synthesize Qualitative Literature in Psychiatry. *Frontiers in Psychiatry*, 8. Doi:10.3389/fpsyt.2017.00269

Lancaster University (2009). *Research Ethics and Research Governance: a code of practice: GAP/2009/0521*. Lancaster; Lancaster University.

Lancaster University (2015). *Research Data Policy. SEC/2015/2/0416*. Lancaster; Lancaster University.

Landscape Institute (2013). *Public Health and Landscape: Creating healthy places*. London, Landscape Institute.

Lange, C. G. (1912). The mechanism of the emotions (B. Rand, Trans.). In B. Rand (Ed.), *The classical psychologists* (pp. 672–684). Copenhagen (Original work published 1885, *Om Sindsbevaegelser et Psyko-Fysiologisk Studie*). Retrieved from: <https://psychclassics.yorku.ca/Lange/>

Lapadat, J. C. (2017). Ethics in Autoethnography and Collaborative Autoethnography. *Qualitative Inquiry*, 23 (8): 589-603. doi:10.1177/1077800417704462

Laureys, S., & Tononi, G. (2011). *The Neurology of Consciousness: Cognitive Neuroscience and Neuropathology*. Cambridge, MA: Academic Press.

- Lawrence-Wilkes, L. & Ashmore, L. (2014). *The Reflective Practitioner in Professional Education*. Basingstoke: Palgrave Macmillan.
- Leafgren, S. L. (2016) *Reuben's Fall: A Rhizomatic Analysis of Disobedience in Kindergarten*. Routledge: Abingdon, Oxon.
- Lee, M., Laurenson, M., & Whitfield, C. (2012). Can compassion be taught to lessen the effects of compassion fatigue? *Journal of Care Services Management, 6*(3), 121-130. doi:10.1179/1750168713y.0000000016
- Leibing, A. (2019). Geriatrics and humanism: Dementia and fallacies of care. *Journal of Aging Studies, 100796*. doi:10.1016/j.jaging.2019.100796
- Le Roux, C. S. (2017). Exploring rigour in autoethnographic research. *International Journal of Social Research Methodology, 20*(2), 195-207. doi:10.1080/13645579.2016.1140965
- Liberati, E. G., Gorli, M., Moja, L., Galuppo, L., Ripamonti, S., & Scaratti, G. (2015). Exploring the practice of patient centered care: The role of ethnography and reflexivity. *Social Science & Medicine, 133*, 45-52. doi:10.1016/j.socscimed.2015.03.050
- Lin, W., Xie, Y., Cheng, P., Dong, L., Hung, G., & Chiu, P. (2018). Association of visual hallucinations with very mild degenerative dementia due to dementia with Lewy bodies. *PLOS ONE, 13*(10), e0205909. doi:10.1371/journal.pone.0205909

Linehan, M.M. (1993). *Cognitive Behavioral Treatment for Borderline Personality Disorder*. New York : Guilford Press

Linehan, M.M. (1993a). *Skills Training Manual for Treating Borderline Personality Disorder*. New York: Guilford Press.

Linszen, M. M., Lemstra, A. W., Dauwan, M., Brouwer, R. M., Scheltens, P., & Sommer, I. E. (2018). Understanding hallucinations in probable Alzheimer's disease: Very low prevalence rates in a tertiary memory clinic. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, *10*, 358-362.  
doi:10.1016/j.dadm.2018.03.005

Liu, W., Zhao, S., Shi, L., Zhang, Z., Liu, X., Li, L., ... Ni, X. (2018). Workplace violence, job satisfaction, burnout, perceived organisational support and their effects on turnover intention among Chinese nurses in tertiary hospitals: a cross-sectional study. *BMJ Open*, *8*(6), e019525. doi:10.1136/bmjopen-2017-019525

Liu, Y., Su, P., Chen, C., Chiang, H., Wang, K., & Tzeng, W. (2011). Facing death, facing self: nursing students' emotional reactions during an experiential workshop on life-and-death issues. *Journal of Clinical Nursing*, *20*(5-6), 856-863. doi:10.1111/j.1365-2702.2010.03545.x

- MacDonald, S. M. (2016). Composing an Autoethnographic Cartography of Blue: Becoming a Pharologist in and of the Academy. *Cultural Studies ↔ Critical Methodologies*, 18(2), 149-162. doi:10.1177/1532708616673654
- MacNaughton, G. (2003). *Shaping Early Childhood: Learners, Curriculum and Contexts*. Milton Keynes, United Kingdom: McGraw-Hill Education (UK).
- MacNaughton, G. (2005) *Doing Foucault in Early Childhood Studies: applying poststructural ideas*. Abingdon: Routledge. Retrieved from: <http://dx.doi.org/10.4324/9780203465332>
- Malacrida, C. (2007). Reflexive Journaling on Emotional Research Topics: Ethical Issues for Team Researchers. *Qualitative Health Research*, 17 (10): 1329-1339. doi:10.1177/1049732307308948
- Manning, J., & Adams, T. (2015). Popular culture studies and autoethnography: An essay on method. *The Popular Culture Studies Journal*, 3 (1&2): 187–222.
- Manojlovich, M. (2007). Power and Empowerment in Nursing: Looking Backward to Inform the Future. *OJIN: The Online Journal of Issues in Nursing*. 12 (1): Manuscript 1. Doi:10.3912/OJIN.Vol12No01Man01
- Mantzorou, M., & Mastrogiannis, D. (2011). The Value and Significance of Knowing the Patient for Professional Practice, according to the Carper's Patterns of Knowing. *Health Science Journal*, 5 (4): 251–261.

- Maréchal, G. (2010). *Autoethnography*. In A. J. Mills, G. Durepos & E. Wiebe (Eds.), *Encyclopedia of case study research* (Vol. 2, pp. 43–45). Thousand Oaks, CA: Sage Publications.
- Marsh, P., Courtney-Pratt, H., & Campbell, M. (2018). The landscape of dementia inclusivity. *Health & Place*, 52: 174-179.  
Doi:10.1016/j.healthplace.2018.05.013
- Martin J-C. (2010). *Variations: The Philosophy of Gilles Deleuze*. Translated by Constantin V. Boundas. Edinburgh: Edinburgh University Press.
- Masny, D. (2013). Rhizoanalytic pathways in qualitative research. *Qualitative Inquiry*, 19 (5): 339-348.
- Masny, D. (2014). Disrupting Ethnography through Rhizoanalysis. *Qualitative Research in Education*, 3 (3): 345-363. Doi: 10.4471/qre.2014.51
- Masny, D. (2015). Problematizing qualitative educational research: reading observations and interviews through rhizoanalysis and multiple literacies. *Reconceptualizing Educational Research Methodology*, 6(1).  
doi:10.7577/term.1422
- Masny, D. (2018). Becoming Childhoodnature: Experimenting a Research Assemblage. In Raby, R. L., & Valeau, E. J. (2018). *Handbook of*

*Comparative Studies on Community Colleges and Global Counterparts.*  
Basingstoke, England: Springer (p. 1-18).

Masny, D. & Cole, D.R. (2014) *Mapping Multiple Literacies: An Introduction to Deleuzian Literacy Studies.* London: Bloomsbury.

Masny, D., & Waterhouse M. (2011). Mapping territories and creating nomadic pathways with multiple literacies theory. *Journal of Curriculum Theorizing.* 27(3): 287-307. Retrieved from:  
<https://journal.jctonline.org/index.php/jct/article/view/155>

Matthews, B. (2013). Faculty of 1000 evaluation for Care in specialist medical and mental health unit compared with standard care for older people with cognitive impairment admitted to general hospital: randomised controlled trial (NIHR TEAM trial). *F1000 - Post-publication peer review of the biomedical literature.* doi:10.3410/f.718052117.793483286

McCartney M (2017) Margaret McCartney: Nurses must be allowed to exercise professional judgment. *British Medical Journal*; 356: j1548.

McEvoy, P., Baker, D., Plant, R., Hylton, K., & Mansell, W. (2012). Empathic curiosity: resolving goal conflicts that generate emotional distress. *Journal of Psychiatric and Mental Health Nursing*, 20 (3): 273-278. Doi:10.1111/j.1365-2850.2012.01926.x

- McEvoy, P., & Plant, R. (2014). Dementia care: using empathic curiosity to establish the common ground that is necessary for meaningful communication. *Journal of Psychiatric and Mental Health Nursing*, 21 (6): 477-482.  
Doi:10.1111/jpm.12148
- McGraw, J.J. (2012). What is Intersubjectivity? *THERE Journal of Design* (8): 72-77.  
Retrieved from:  
[https://www.academia.edu/5254097/\\_Article\\_What\\_is\\_Intersubjectivity](https://www.academia.edu/5254097/_Article_What_is_Intersubjectivity)
- McIlveen, P. (2008). Autoethnography as a Method for Reflexive Research and Practice in Vocational Psychology. *Australian Journal of Career Development*, 17 (2): 13-20. doi:10.1177/103841620801700204
- McIntyre, A. (2008). *Participatory Action Research*. Thousand Oaks, CA: SAGE.
- McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2009). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19(13-14), 1935-1943. doi:10.1111/j.1365-2702.2009.03136.x
- Mead, G., & Morris, C. (1934). *Mind, self & society from the standpoint of a social behaviorist*. Chicago, Ill.: University of Chicago Press.
- Medford, K. (2006). Caught With a Fake ID. *Qualitative Inquiry*, 12 (5): 853-864.  
Doi:10.1177/1077800406288618

- Melander, C., Sävenstedt, S., Olsson, M., & Wälivaara, B. (2017). Assessing BPSD with the support of the NPI-NH: a discourse analysis of clinical reasoning. *International Psychogeriatrics*, 30(4), 581-589.  
doi:10.1017/s1041610217002009
- Méndez, M. G. (2014). Autoethnography as a research method: Advantages, limitations and criticisms. *Colombian Applied Linguistics Journal*, 15 (2): 279.  
Doi:10.14483/udistrital.jour.calj.2013.2.a09
- Methley, A. M., Campbell, S., Chew-Graham, C., McNally, R., & Cheraghi-Sohi, S. (2014). PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. *BMC Health Services Research*, 14(1). doi:10.1186/s12913-014-0579-0
- Mills, J., Wand, T., & Fraser, J. A. (2015). On self-compassion and self-care in nursing: Selfish or essential for compassionate care? *International Journal of Nursing Studies*, 52(4), 791-793. doi:10.1016/j.ijnurstu.2014.10.009
- Minge, J. M., & Zimmerman, A. L. (2013). *Concrete and dust: Mapping the sexual terrains of Los Angeles*. New York, NY: Routledge.
- Mograbi, D. C., Brown, R. G., Landeira-Fernandez, J., & Morris, R. G. (2014). Metacognition and attribution of difficulty for self and others in Alzheimer's disease. *Psychology & Neuroscience*, 7 (3): 417-424.  
Doi:10.3922/j.psns.2014.036

- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PloS Med* 6 (7): e1000097.  
Doi:10.1371/journal.pmed1000097
- Monthaisong, D. (2018). Nurses' Experiences Providing Care for People with Dementia: An Integrative Literature Review. *Journal of Nursing & Care*, 07(02). doi:10.4172/2167-1168.1000453
- Moonga, J., & Likupe, G. (2016). A systematic literature review on nurses' and health care support workers' experiences of caring for people living with dementia on orthopaedic wards. *Journal of Clinical Nursing*, 25 (13-14): 1789-1804.  
Doi:10.1111/jocn.13158
- Moore, L., Britten, N., Lydahl, D., Naldemirci, Ö., Elam, M., & Wolf, A. (2016). Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian Journal of Caring Sciences*, 31(4), 662-673. doi:10.1111/scs.12376
- Moreau, N., Viallet, F., & Champagne-Lavau, M. (2013). Using memories to understand others: The role of episodic memory in theory of mind impairment in Alzheimer disease. *Ageing Research Reviews*, 12 (4): 833-839.  
Doi:10.1016/j.arr.2013.06.005
- Morse, J. (2002). Writing my own experience. *Qualitative Health Research*, 12 (9): 1159-1160. Doi:10.1177/1049732302238241

Mudallal, R. H., Othman, W. M., & Al Hassan, N. F. (2017). Nurses' Burnout: The Influence of Leader Empowering Behaviors, Work Conditions, and Demographic Traits. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, 54: 004695801772494.  
Doi:10.1177/0046958017724944

Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: approaches and goals. *Aging Health*, 8(4), 377-386.  
doi:10.2217/ahe.12.42

Mukaetova-Ladinska, E. (2016). Current and Future Perspectives of Liaison Psychiatry Services: Relevance for Older People's Care. *Geriatrics*, 1 (1): 7.  
Doi:10.3390/geriatrics1010007

Muncey, T. (2010). *Creating autoethnographies*. Los Angeles: SAGE.

Murphy, D. (2015) (ed) "Concepts of Disease and Health", *The Stanford Encyclopedia of Philosophy* (Spring 2015 Edition). Retrieved from:  
<https://plato.stanford.edu/archives/spr2015/entries/health-disease>

Nadin, S., & Cassell, C. (2006). The use of a research diary as a tool for reflexive practice. *Qualitative Research in Accounting & Management*, 3 (3): 208-217.  
Doi:10.1108/11766090610705407

Naidu, S., Bolton, J., & Smith, J. (2015). London's liaison psychiatry services: survey of service provision. *BJPsych Bulletin*, 39 (2): 65-69.

Doi:10.1192/pb.bp.114.046862

National Nursing Research Unit, (2009) *Nursing competence: what are we assessing and how should it be measured?* Policy plus, London: King's College London.

Retrieved from: <https://www.kcl.ac.uk/nursing/research/nnru/policy/policy-plus-issues-by-theme/boundaries-regulation-competence/policyissue18.pdf>

Nayak, A., & Chia, R. (2011). Thinking becoming and emergence: process philosophy and organization studies. *Philosophy and Organization Theory*, 281-309.

doi:10.1108/s0733-558x(2011)0000032012

Neiger, M., Meyers, O., & Zandberg, E. (2011). *On Media Memory: Collective Memory in a New Media Age*. Basingstoke, England: Springer.

Newman, S. (2003). Empiricism, Pluralism, and Politics in Deleuze and Stirner.

*Idealistic Studies*, 33(1), 9-24. doi:10.5840/idstudies20033312

Ngunjiri, F. W., Hernandez, K. C., & Chang, H. (2010). Living autoethnography:

Connecting life and research [Editorial]. *Journal of Research Practice*, 6 (1):

Article E1. Retrieved

from: <http://jrp.icaap.org/index.php/jrp/article/view/241/186>

NHS Choices (2017). *Dementia Guide*. Retrieved from:

<https://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx>

NHS England, the National Collaborating Centre for Mental Health and the National

Institute for Health and Care Excellence (2016). *Achieving Better Access to 24/7 Urgent and Emergency Mental Health Care – Part 2: Implementing the*

*Evidence-based Treatment Pathway for Urgent and Emergency Liaison*

*Mental Health Services for Adults and Older Adults – Guidance*. Retrieved

from: <https://www.england.nhs.uk/wp-content/uploads/2016/11/lmhs-guidance.pdf>

NHS Institute for Innovation and Improvement. (2011) An economic evaluation of

alternatives to antipsychotic drugs for individuals living with dementia. *The*

*NHS Institute for Innovation and Improvement*, Coventry House, University of

Warwick Campus, Coventry, UK.

NICE (2018) NICE guideline [NG97]. Dementia: assessment, management and

support for people living with dementia and their carers. London: NICE.

NICE- SCIE (2006). *NICE guideline 42 – Dementia: supporting people living with*

*dementia and their carers in health and social care*. London, NICE-SCIE.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative*

*studies*. London: SAGE.

- Nolte, A. G., Downing, C., Temane, A., & Hastings-Tolsma, M. (2017). Compassion fatigue in nurses: A metasynthesis. *Journal of Clinical Nursing*, 26(23-24), 4364-4378. doi:10.1111/jocn.13766
- Norouzinia, R., Aghabarari, M., Shiri, M., Karimi, M., & Samami, E. (2015). Communication Barriers Perceived by Nurses and Patients. *Global Journal of Health Science*, 8(6), 65. doi:10.5539/gjhs.v8n6p65
- Nowakowski, A. C. H. (2016). You Poor Thing: A Retrospective Autoethnography of Visible Chronic Illness as Symbolic Vanishing Act. *The Qualitative Report*, 21(9): 1615-1635.
- Nunez, K. M., Khan, Z., Testad, I., Lawrence, V., Creese, B., & Corbett, A. (2017). Current practice and challenges in night-time care for people with dementia living in care homes: a qualitative study. *International Journal of Geriatric Psychiatry*, 33(1), e140-e149. doi:10.1002/gps.4737
- Nursing & Midwifery Council. (2018). *The code: Professional standards of practice and behaviour for nurses, midwives and nursing associates*. London: Nursing & Midwifery Council.
- Nutsford, D., Pearson, A. L., Kingham, S., & Reitsma, F. (2016). Residential exposure to visible blue space (but not green space) associated with lower psychological distress in a capital city. *Health & Place*, 39: 70-78.  
doi:10.1016/j.healthplace.2016.03.002

- Oflaz, F., Meric, M., Yuksel, Ç., & Ozcan, C. T. (2011). Psychodrama: an innovative way of improving self-awareness of nurses. *Journal of Psychiatric and Mental Health Nursing, 18*(7), 569-575. doi:10.1111/j.1365-2850.2011.01704.x
- Ohlin, J. D. (2005). Is the Concept of the Person Necessary for Human Rights? *International Legal Personality, 437-478*.  
doi:10.4324/9781315092485-19
- Pai, H. (2015). The Effect of a Self-Reflection and Insight Program on the Nursing Competence of Nursing Students: A Longitudinal Study. *Journal of Professional Nursing, 31*(5), 424-431. doi:10.1016/j.profnurs.2015.03.003
- Palaganas, E. C., Sanchez, M. C., Molintas, M. P., & Caricativo, R. D. (2017). Reflexivity in Qualitative Research: A Journey of Learning. *The Qualitative Report, 22*(2), 426-438. Retrieved from  
<https://nsuworks.nova.edu/tqr/vol22/iss2/5>
- Palese, A., Menegazzo, E., Baulino, F., Pistrino, R., & Papparotto, C. (2009). The Effectiveness of Multistrategies on Disruptive Vocalization of People With Dementia in Institutions. *Journal of Neuroscience Nursing, 41*(4), 191-200.  
doi:10.1097/jnn.0b013e3181aaaab2
- Parr, A. (2005). *The Deleuze dictionary*. Edinburgh: Edinburgh University Press.

Patnaik, E. (2013). Reflexivity: Situating the researcher in qualitative research.

*Humanities and Social Science Studies*. 2 (2): 98-106.

Paudyal, V., Cunningham, S., Gibson Smith, K., MacLure, K., Ryan, C. and Cordina,

M. (2018). Methodological considerations in clinical outcomes assessment of

pharmacy-based minor ailments management: A systematic review. *PLOS*

*ONE*, 13 (10): doi.org/10.1371/journal.pone.0205087.

Pennsylvania Echoes (2011). *Intersubjectivity and Interpersonal Brighter Side*.

Retrieved from: <https://echopen.wordpress.com/2011/12/05/intersubjectivity-and-interpersonal-brighter-side/>

Pensoneau-Conway, S.L., Adams, T.E., & Bolen, D.M. (2017). *Doing*

*Autoethnography*. Sense Publishers, Rotterdam. [https://doi.org/10.1007/978-94-6351-158-2\\_1](https://doi.org/10.1007/978-94-6351-158-2_1)

Pierson, W. (1999). Considering the nature of intersubjectivity within professional

nursing. *Journal of Advanced Nursing*, 30 (2): 294-302. Doi:10.1046/j.1365-

2648.1999.01081.x

Pippin, R. B. (Ed) & Del Caro. A, (Trans) (2006). *Nietzsche: Thus spoke Zarathustra:*

*A book for all and none*. Cambridge: Cambridge University Press.

- Pitard, J. (2016). Using Vignettes Within Autoethnography to Explore Layers of Cross-Cultural Awareness as a Teacher, *Qualitative Social Research*, 17 (1): Article 11.
- Pitard, J. (2017). 'A Journey to the Centre of Self: Positioning the Researcher in Autoethnography.' *Forum: Qualitative Social Research*, 18 (3): 108-127.
- Polit, D. F., & Beck, C. T. (2010). *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. Philadelphia, PA: Lippincott Williams & Wilkins.
- Premack, D., & Woodruff, G. (1978). Does the chimpanzee have a theory of mind? *Behavioral and Brain Sciences*, 1 (04): 515. Doi:10.1017/s0140525x00076512
- Price, B. (2016). Hallucinations: insights and supportive first care. *Nursing Standard*, 30(21), 49-60. doi:10.7748/ns.30.21.49.s45
- Price, B. (2017). Improving nurses' level of reflection. *Nursing Standard*, 32 (1): 52-63. Doi:10.7748/ns.2017.e10900
- Rae, G. (2014). Traces of Identity in Deleuze's Differential Ontology. *International Journal of Philosophical Studies*, 22 (1): 86-105. DOI: 10.1080/09672559.2013.861003

- Rambo, C. (2007). Handing IRB an Unloaded Gun. *Qualitative Inquiry*, 13 (3): 353-367. doi:10.1177/1077800406297652
- Ramey, H. L., & Grubb, S. (2009). Modernism, Postmodernism and (Evidence-Based) Practice. *Contemporary Family Therapy*, 31 (2): 75-86. doi:10.1007/s10591-009-9086-6
- Randolph, R. (2016) *In medias res*. Unpublished Poem. Retrieved from:  
<https://www.poemhunter.com/poem/in-medias-res/>
- Rapaport, P., Livingston, G., & Cooper, C. (2017). How Do Care Home Staff Experience, Understand And Manage Agitation In Residents With Dementia? A Qualitative Study. *Alzheimer's & Dementia*, 13(7), P1411.  
doi:10.1016/j.jalz.2017.06.2187
- Redwood, S. (2008) 'Research Less Violent? On the Ethics of Performative Social Science',  
Forum: *Qualitative Social Research*, 9 (2): Article 60. Retrieved from:  
<http://www.qualitativeresearch.net/index.php/fqs/article/view/407/882>
- Reyes, G. (2015). *Introspection of complex cognitive processes*. Cognitive Sciences. Université Pierre et Marie Curie – Paris. Retrieved from: <https://tel.archives-ouvertes.fr/tel-01331023/document>

Richards, L. (2015). *Handling qualitative data: a practical guide*. 3<sup>rd</sup> ed. London: SAGE.

Richardson L (1997) *Fields of Play: Constructing an Academic Life*. New Brunswick, NJ: Rutgers University Press.

Richardson, M. (2001). *The experience of culture*. London: SAGE.

Richardson, C., Percy, M., & Hughes, J. (2015). Nursing therapeutics: Teaching student nurses care, compassion and empathy. *Nurse Education Today*, 35(5), e1-e5. doi:10.1016/j.nedt.2015.01.016

Riessmann, C. (2008). *Narrative Methods for the Human Sciences*. Thousand Oaks: SAGE.

Ritchie, J. & Spencer, L. (1994). *Qualitative data analysis for applied policy research* in A. Bryman and R. G. Burgess [eds.] *'Analysing qualitative data'*, (pp.173-194). London: Routledge

Robinson, A. (2017). *Chaos or Kaleidoscope? A Friday in the Life of an Elementary School Principal*. Self-Reg Community, The MEHRIT Centre (TMC) online blog. Retrieved from: <https://self-reg.ca/2017/01/31/chaos-or-kaleidoscope/>

Robinson, L., & Maguire, M. (2010). The rhizome and the tree: changing metaphors for information organisation. *Journal of Documentation*, 66(4), 604-613.  
doi:10.1108/00220411011052975

Rochat, P.; Passos-Ferreira, C.; Salem, P. (2009). *Three Levels of Intersubjectivity in Early Development In: Enacting Intersubjectivity. Paving the way for a dialogue between cognitive science, social cognition and neuroscience* (pp. 173-190). Como: da Larioprint.

Rodriquez, J. (2009). Attributions of Agency and the Construction of Moral Order: Dementia, Death, and Dignity in Nursing-home Care. *Social Psychology Quarterly*, 72 (2): 165-179. doi:10.1177/019027250907200206

Roever C.P., Vyas, B. B., Barnett, M. C., Sheyner, I., & Stewart, J. T. (2012) Visual hallucinations in long-term care. *Annals of Long-Term Care: Clinical Care and Aging*. 20(2):25-30.

Rogers, C. R. (1975). Empathic: An Unappreciated Way of Being. *The Counselling Psychologist*, 5 (2): 2-10. doi:10.1177/001100007500500202

Rogers, C. R. (1995). *A Way of Being*. Boston, MA: Houghton Mifflin Harcourt.

Ronai, C. R. (1992). *The reflexive self through narrative: A night in the life of an erotic dancer/researcher*. In Ellis, C. & Flaherty, M.G. (eds.) *Investigating*

*subjectivity: Research on lived experience* (pp.102-124). Newbury Park, CA: Sage.

Ronai, C. R. (1995). Multiple Reflections of Child Sex Abuse: An Argument for a Layered Account. *Journal of Contemporary Ethnography*, 23 (4): 395-426.  
doi:10.1177/089124195023004001

Rosen, H. J., Alcanta,r O., Shimamura, A., Neuhaus, J., & Miller, B. L. (2014). Metacognition in the behavioural variant of frontotemporal dementia and Alzheimer's disease. *Neuropsychology*, 28 (3): 436-47.

Rosenwohl-Mack, A., Schumacher, K., Fang, M., & Fukuoka, Y. (2018). Experiences of aging in place in the United States: protocol for a systematic review and meta-ethnography of qualitative studies. *Systematic Reviews*, 7 (1).  
Doi:10.1186/s13643-018-0820-8

Ross, H., Tod, A. M., & Clarke, A. (2014). Understanding and achieving person-centred care: the nurse perspective. *Journal of Clinical Nursing*, 24 (9-10): 1223-1233. Doi:10.1111/jocn.12662

Roth, W.-M. (2009). Auto/ethnography and the question of ethics, *Forum: Qualitative Social Research* 10 (1): 38. Retrieved from:  
<http://www.qualitative-research.net/index.php/fqs/article/view/1213/2645>

- Rouch, I., Dorey, J., Boublay, N., Henaff, M., Dibie-Racoupeau, F., & Krolak-Salmon, P. et al., (2014). Personality, Alzheimer's disease and behavioural and cognitive symptoms of dementia: the PACO prospective cohort study protocol. *BMC Geriatrics*, 14 (1). doi:10.1186/1471-2318-14-110
- Royal College of Nursing (RCN) (2011). *Dignity in Dementia; findings from survey of carers and people living with dementia*. London: RCN.
- Royal College of Psychiatrist (2005). *Atypical Antipsychotics and Behavioural and Psychiatric Symptoms of Dementia*. Royal College of Psychiatrists, London.  
Retrieved from: <http://www.rcpsych.ac.uk/PDF/BPSD.pdf>
- Sabo, B. M., & Vachon, M. L. (2011). Care of professional caregivers. *Supportive Oncology*, (56):575-589. doi:10.1016/b978-1-4377-1015-1.00056-4
- Sambrook, S. (2015). *In (re)search of the self: Autoethnography in HRD research*. In Handbook of Research Methods on Human Resource Development. Edward Elgar, pp. 92-107. ISBN 9781781009239
- Sampson, E. L., White, N., Leurent, B., Scott, S., Lord, K., Round, J., & Jones, L. (2014). Behavioural and psychiatric symptoms in people living with dementia admitted to the acute hospital: prospective cohort study. *The British Journal of Psychiatry*, 205 (3): 189-196. Doi:10.1192/bjp.bp.113.130948

- Scales, K., Zimmerman, S., & Miller, S. J. (2018). Evidence-Based Nonpharmacological Practices to Address Behavioral and Psychological Symptoms of Dementia. *The Gerontologist*, 58 (suppl\_1): S88-S102.  
Doi:10.1093/geront/gnx167
- Schablon, A., Wendeler, D., Kozak, A., Nienhaus, A., & Steinke, S. (2018). Prevalence and Consequences of Aggression and Violence towards Nursing and Care Staff in Germany—A Survey. *International Journal of Environmental Research and Public Health*, 15(6), 1274.  
doi:10.3390/ijerph15061274
- Schutz, A. (1964). *Collected Papers II: Studies in Social Theory*. New York: Humanities Press.
- Schutz, A. (1966). *The Problem of Transcendental Intersubjectivity in Husserl*, in *Collected Papers*, Vol. 3, pp. 51–83. The Hague: Martinus Nijhoff.
- Schutz, A. (1967). *The phenomenology of the social world*. Translated by George Walsh and Frederick Lehnert; with an introduction by George Walsh. London: Heinemann Educational.
- Schwandt, T. A. (1994). *Constructivist, interpretivist approaches to human inquiry*. In Denzin, N.K., & Lincoln, Y.S. (ed.), *Handbook of qualitative research*. Thousand Oaks: Sage, pp. 118-137.

- Schwartenbeck, P., FitzGerald, T. H., Mathys, C., Dolan, R., Wurst, F., Kronbichler, M., & Friston, K. (2016). Corrigendum to 'Optimal inference with suboptimal models: Addiction and active Bayesian inference'. *Medical Hypotheses*, 91, 123. doi:10.1016/j.mehy.2016.02.021
- Scott, J. G., Scott, R. G., Miller, W. L., Stange, K. C., & Crabtree, B. F. (2009). Healing relationships and the existential philosophy of Martin Buber. *Philosophy, Ethics, and Humanities in Medicine*, 4 (1): 11. doi:10.1186/1747-5341-4-11
- Sellers, M. (2015). ...working with (a) rhizoanalysis...and...working (with) a rhizoanalysis.... *Complicity: An International Journal of Complexity and Education*, 12(1). doi:10.29173/cmplct23166
- Semetsky, I. (2004). The complexity of individuation. *International Journal of Applied Psychoanalytic Studies*, 1 (4): 324-346. doi:10.1002/aps.84
- Semetsky, I. (2011). Becoming-other: Developing the Ethics of Integration. *Policy Futures in Education*, 9 (1): 138-144. doi:10.2304/pfie.2011.9.1.138
- Siegel, D. J. (2007). Mindfulness training and neural integration: differentiation of distinct streams of awareness and the cultivation of well-being. *Social Cognitive and Affective Neuroscience*, 2(4), 259-263. doi:10.1093/scan/nsm034

- Siewdass, P. (2017) Response - Margaret McCartney: Nurses must be allowed to exercise professional judgment. *British Medical Journal*. 356.  
doi.org/10.1136/bmj.j1548
- Sikes, P. (2010). *The Ethics of Writing Life Histories and Narratives in Educational Research.* In Bathmaker, A. & Harnett, P. (eds.) *Exploring Learning, Identity and Power Through Life History and Narrative Research*. London: Routledge/Falmer.
- Sikes, P. (2015). *Ethical Considerations in Autoethnographic Research: Specialist Research Ethics Guidance Paper*. School of Education, University of Sheffield. Retrieved from:  
[https://www.sheffield.ac.uk/polopoly\\_fs/1.586562!/file/SREGP-Autoethnography-2015.pdf](https://www.sheffield.ac.uk/polopoly_fs/1.586562!/file/SREGP-Autoethnography-2015.pdf)
- Simm, L. A., Jamieson, R. D., Ong, B., Garner, M. W., & Kinsella, G. J. (2015). Making sense of self in Alzheimer's disease: reflective function and memory. *Aging & Mental Health*, 21(5), 501-508. doi:10.1080/13607863.2015.1120706
- Smith, D. W. (2012). *Essays on Deleuze*. Edinburgh, Scotland: Edinburgh University Press.
- Smith, D. W. (2013). Temporality and Truth. *Deleuze Studies*, 7 (3): 377-389.  
Doi:10.3366/dls.2013.0118

- Smith, J. (2011). Can intersubjectivity be naturalized? *Phenomenology and the Cognitive Sciences*, 10 (1): 91-111. DOI 10.1007/s11097-009-9149-z
- Smith, S. (2015). *PhD by Published Work: A Practical Guide for Success*. London, United Kingdom: Macmillan International Higher Education.
- Smith, K. E., & Anderson, R. (2018). Understanding lay perspectives on socioeconomic health inequalities in Britain: A meta-ethnography. *Sociology of Health & Illness*, 40(1), 146–170. doi.10.1111/1467-9566.12629
- Smith, T. O, Latham, S., Maskrey, V., & Blyth, A. (2015). Patients' perceptions of physical activity before and after joint replacement: a systematic review with meta-ethnographic analysis. *Postgraduate Medical Journal*. 91 (1079): 483–491. doi: 10.1136/postgradmedj-2015-133507
- Sorroza Lopez, L. A., & Martino-Roaro, L. (2016) Pharmaco-economic Approach to Dementia: A Review of the Current Pharmacological and Non-Pharmacological Managements – A Cost-Benefit Analysis. *International Journal of Psychiatry* 1(2):1-11. Retrieved from: <https://www.opastonline.com/ijp-volume-1-issue-2-year-2016/>
- Spector, A., Orrell, M., & Goyder, J. (2013). A systematic review of staff training interventions to reduce the behavioural and psychological symptoms of dementia. *Ageing Research Reviews*, 12(1), 354-364. doi:10.1016/j.arr.2012.06.005

- Spry, T. (2001). Performing Autoethnography: An Embodied Methodological Praxis. *Qualitative Inquiry*, 7 (6): 706-732.  
Doi:10.1177/107780040100700605
- Srivastava, P., & Hopwood, N. (2009). A Practical Iterative Framework for Qualitative Data Analysis. *International Journal of Qualitative Methods*, 8 (1): 76-84. Doi:10.1177/160940690900800107
- Stacey, G., Joynson, K., Diamond, B. & Stickley, T., (2011). How do nurses cope when values and practice conflict, *Nursing Times*. 107 (5): 20 – 24.
- Stahlke Wall, S. (2016). Toward a Moderate Autoethnography. *International Journal of Qualitative Methods*, 15(1), 160940691667496.  
doi:10.1177/1609406916674966
- Stanley, S. (2013). ‘Things said or done long ago are recalled and remembered’: The ethics of mindfulness in early Buddhism, psychotherapy and clinical psychology. *European Journal of Psychotherapy & Counselling*, 15 (2): 151-162. Doi:10.1080/13642537.2013.795338
- Stansfield, R. B., Schwartz, A., O’Brien, C. L., Dekhtyar, M., Dunham, L., & Quirk, M. (2015). Development of a metacognitive effort construct of empathy during clinical training: a longitudinal study of the factor structure of the Jefferson Scale of Empathy. *Advances in Health Sciences Education*, 21 (1): 5-17. doi:10.1007/s10459-015-9605-1

- St. Pierre, E. A. (2017). Writing Post Qualitative Inquiry. *Qualitative Inquiry*, 24(9), 603-608. doi:10.1177/1077800417734567
- Strom, K. J., & Martin, A. D. (2013). Putting Philosophy to Work in the Classroom: Using Rhizomatics to Deterritorialize Neoliberal Thought and Practice. *Studying Teacher Education*, 9 (3): 219-235.  
Doi:10.1080/17425964.2013.830970
- Styhre, A. (2001). *We have never been Deleuzians: desire, immanence, motivation, and the absence of Deleuze in organization theory*, paper presented to the 2<sup>nd</sup> Critical Management Studies Conference, Manchester, 11-13 July. Retrieved from:  
<http://www.http://www.mngt.waikato.ac.nz/ejrot/cmsconference/2001/Papers/Passion%20for%20Organising/Styhre.pdf>
- Sukovic, S. (2008). Information Discovery in Ambiguous Zones of Research. *Library Trends*, 57(1), 82-87. doi:10.1353/lib.0.0025
- Sunderaraman, P., & Cosentino, S. (2017). Integrating the Constructs of Anosognosia and Metacognition: a Review of Recent Findings in Dementia. *Current Neurology and Neuroscience Reports*, 17 (3). Doi:10.1007/s11910-017-0734-1
- Svanström, R., Sundler, A. J., Berglund, M., & Westin, L. (2013). Suffering caused by care—elderly patients’ experiences in community care. *International Journal*

*of Qualitative Studies on Health and Well-being*, 8 (1): 1-10.

Doi:10.3402/qhw.v8i0.20603

Tampi, R., Tampi, D., Balachandran, S., & Srinivasan, S. (2017). Antipsychotic Use in Dementia: A Systematic Review of Benefits and Risks from Meta-Analyses. *The American Journal of Geriatric Psychiatry*, 25(3), S81.

doi:10.1016/j.jagp.2017.01.087

Tampio, N. (2010) "Multiplicity" p.494-498. In Bevir, M. (Ed) (2010). *Encyclopedia of Political Theory*. Thousand Oaks, CA: SAGE Publications.

Taylor, J. S. (2008). On Recognition, Caring, and Dementia. *Medical Anthropology Quarterly*, 22 (4): 313-335. doi:10.1111/j.1548-1387.2008.00036.x

Taylor, J., Firbank, M., Barnett, N., Pearce, S., Livingstone, A., Mosimann, U. ...

O'Brien, J. T. (2011). Visual hallucinations in dementia with Lewy bodies: transcranial magnetic stimulation study. *British Journal of Psychiatry*, 199(6), 492-500. doi:10.1192/bjp.bp.110.090373

Thiele, K. (2016). Of Immanence and Becoming: Deleuze and Guattari's Philosophy and/as Relational Ontology. *Deleuze Studies*, 10 (1): 117-134.

Doi:10.3366/dls.2016.0215

Thompson R. (2011) Using life story work to enhance care. *Nursing Older People* 23 (8): 16-21. doi: 10.7748/nop2011.10.23.8.16.c8713

- Tible, O. P., Riese, F., Savaskan, E., & Von Gunten, A. (2017). Best practice in the management of behavioural and psychological symptoms of dementia. *Therapeutic Advances in Neurological Disorders*, 10 (8): 297-309. Doi:10.1177/1756285617712979
- Tolich, M. (2004). Internal Confidentiality: When Confidentiality Assurances Fail Relational Informants. *Qualitative Sociology*, 27 (1): 101-106. Doi:10.1023/b:quas.0000015546.20441.4a
- Tolich, M. (2010). A Critique of Current Practice: Ten Foundational Guidelines for Autoethnographers. *Qualitative Health Research*. 20 (12): 1599-1610. Doi: 10.1177/1049732310376076
- Timmons, S., O'Shea, E., O'Neill, D., Gallagher, P., De Siún, A., McArdle, D., ... Kennelly, S. (2016). Acute hospital dementia care: results from a national audit. *BMC Geriatrics*, 16(1). doi:10.1186/s12877-016-0293-3
- Tong, A. Flemming, K., McInnes, E., Oliver, S. & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*. (12): 181-189. 10.1186/1471-2288-12-181.
- Toon, D. P. (2014). *A Flourishing Practice?* London: Royal College of General Practitioners.

- Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., Andrews, J., & Barker, K. (2013). 'Trying to pin down jelly' – exploring intuitive processes in quality assessment for meta-ethnography. *BMC Medical Research Methodology*, *13*(1). Doi:10.1186/1471-2288-13-46
- Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., & Barker, K. (2014). Meta-ethnography 25 years on: challenges and insights for synthesising a large number of qualitative studies. *BMC Medical Research Methodology*, *14*(1). Doi:10.1186/1471-2288-14-80
- Trahar, S. (2013). Autoethnographic Journeys in Learning and Teaching in Higher Education. *European Educational Research Journal*, *12*(3), 367-375. doi:10.2304/eej.2013.12.3.367
- Tranvåg, O., Petersen, K., & Nåden, D. (2013). Dignity-preserving dementia care: A metasynthesis. *Nursing Ethics*, *20* (8): 861-880. Doi:10.1177/0969733013485110
- Trujillo, J. (2018). Intersubjectivity and the Sociology of Alfred Schutz. *Bulletin d'Analyse Phénoménologique*, *14*(7), 1-30. Retrieved from: <https://popups.uliege.be/1782-2041/>
- Turner, J. (2011). Logic and Ontological Pluralism. *Journal of Philosophical Logic*, *41* (2): 419-448. Doi:10.1007/s10992-010-9167-x

- Tuval-Mashiach, R., Freedman, S., Bargai, N., Boker, R., Hadar, H., & Shalev, A. Y. (2004). Coping with Trauma: Narrative and Cognitive Perspectives. *Psychiatry: Interpersonal and Biological Processes*, 67(3), 280-293. doi:10.1521/psyc.67.3.280.48977
- Ullán, A. M., Belver, M. H., Badía, M., Moreno, C., Garrido, E., Gómez-Isla, J., & Tejedor, L. (2013). Contributions of an artistic educational program for older people with early dementia: An exploratory qualitative study. *Dementia*, 12(4): 425-446. Doi:10.1177/1471301211430650
- Usher, R. (2010). Riding the lines of flight. *European Journal for Research on the Education and Learning of Adults*, 1 (1-2): 67-78. Doi:10.3384/rela.2000-7426.rela0011
- Uy, K. K., & Okubo, Y. (2018). Re-Storying the Trauma Narrative: Fostering Posttraumatic Growth in Cambodian Refugee Women. *Women & Therapy*, 41(3-4), 219-236. doi:10.1080/02703149.2018.1425025
- Valandra, V. (2012). Reflexivity and professional use of self in research: A doctoral student's journey. *Journal of Ethnographic & Qualitative Research*, 6, 204–220.
- Van der Hulst, E., Bak, T. H., & Abrahams, S. (2014). Impaired affective and cognitive theory of mind and behavioural change in amyotrophic lateral

sclerosis. *Journal of Neurology, Neurosurgery & Psychiatry*, 86 (11): 1208-1215. Doi:10.1136/jnnp-2014-309290

Van der Spek, K et al., (2016). Only 10% of the psychotropic drug use for neuropsychiatric symptoms in patients with dementia is fully appropriate. The PROPER I-study. *International Psychogeriatrics*, 28 (10): 1589-1595. Doi:10.1017/s104161021600082x

Verboom, B., Montgomery, P. & Bennett, S. (2016). “What factors affect evidence-informed policymaking in public health? Protocol for a systematic review of qualitative evidence using thematic synthesis.” *Systematic Reviews*. Doi: 10.1186/s13643-016-0240-6.

Vermersch, P. (2009). Describing the Practice of Introspection. *Journal of Consciousness Studies*. 16. 20-57.

Vik, T. A., & Bute, J. J. (2009). Utilizing Crystallization in Qualitative Methods. *Review of Communication*, 9 (4): 340-343. Doi:10.1080/15358590903151211

Völker, S., & Kistemann, T. (2011). The impact of blue space on human health and well-being – Salutogenetic health effects of inland surface waters: A review. *International Journal of Hygiene and Environmental Health*, 214(6), 449-460. doi:10.1016/j.ijheh.2011.05.001

- Voss, D. (2013). Deleuze's Third Synthesis of Time. *Deleuze Studies*, 7(2), 194-216.  
doi:10.3366/dls.2013.0102
- Vyran, K. D. (2006). Expanding Analytic Autoethnography and Enhancing Its Potential. *Journal of Contemporary Ethnography*, 35 (4): 405-409.  
Doi:10.1177/0891241606286977
- Walker, A., Barrett, J. R., Lee, W., West, R. M., Guthrie, E., Trigwell, P., House, A. (2018). Organisation and delivery of liaison psychiatry services in general hospitals in England: results of a national survey. *BMJ Open*, 8 (8), e023091.  
Doi:10.1136/bmjopen-2018-023091
- Wall, S. (2006). An Autoethnography on Learning About Autoethnography. *International Journal of Qualitative Methods*, 5 (2): 146-160. Doi:10.1177/160940690600500205
- Wall, S. (2008). Easier Said than Done: Writing an Autoethnography. *International Journal of Qualitative Methods*, 7 (1): 38-53.  
Doi:10.1177/160940690800700103
- Walsh, K., O'Regan, N., Byrne, S., Browne, J., Meagher, D., & Timmons, S. (2016). Patterns of psychotropic prescribing and polypharmacy in older hospitalized patients in Ireland: The influence of dementia on prescribing. *International Psychogeriatrics*, 28 (11): 1807-1820. Doi:10.1017/S1041610216001307

- Warelow, P. J. (2013). Changing philosophies: a paradigmatic nursing shift from Nightingale. *Australian Journal of Advanced Nursing*, 31 (1): 36-45.
- Weidman, J. C., & Stein, E. L. (2003). 'Socialization of doctoral students to academic norms.' *Research in Higher Education*, 44 (6): 641-656.
- Weinbaum, D. R. (2014). Complexity and the Philosophy of Becoming. *Foundations of Science*, 20 (3): 283-322. doi:10.1007/s10699-014-9370-2
- White, N., Leurent, B., Lord, K., Scott, S., Jones, L., & Sampson, E. L. (2016). The management of Behavioural and Psychological Symptoms of Dementia in the acute general medical hospital: a longitudinal cohort study. *International Journal of Geriatric Psychiatry*, 32 (3): 297-305. doi:10.1002/gps.4463
- Whyte, W. F. (1991). *Participatory action research*. Thousand Oaks, CA: Sage Publications.
- Wicker, A. W. (2011). Perspectives on Behavior Settings. *Environment and Behavior*, 44(4), 474-492. doi:10.1177/0013916511398374
- Williams, J. (2011). *Gilles Deleuze's Philosophy of Time: A Critical Introduction and Guide*. Edinburgh, Scotland: Edinburgh University Press.
- Yanow, D., & Schwartz-Shea, P. (2011). *Interpretive Approaches to Research Design: Concepts and Processes*. Netherlands: Routledge.

Young, T. J., Manthorp, C., Howells, D., & Tullo, E. (2011). Optimizing communication between medical professionals and people living with dementia. *International Psychogeriatrics*, 23(07), 1078-1085.  
doi:10.1017/s1041610211000652

Yountae, A. (2014). Beginning in the Middle: Deleuze, Glissant and Colonial Difference. *Culture, Theory and Critique*, 55 (3): 286-301, doi: 10.1080/14735784.2013.856768

Yous, M., Ploeg, J., Kaasalainen, S., & Martin, L. S. (2019). Nurses' Experiences in Caring for Older Adults with Responsive Behaviors of Dementia in Acute Care. *SAGE Open Nursing*, 5, 237796081983412.  
doi:10.1177/2377960819834127

Yusupov, A., & Galvin, J. E. (2014). Vocalization in Dementia: A Case Report and Review of the Literature. *Case Reports in Neurology*, 6(1), 126-133.  
doi:10.1159/000362159

Zaki, J., & Ochsner, K. N. (2012). The neuroscience of empathy: progress, pitfalls and promise. *Nature Neuroscience*, 15 (5): 675-680. doi:10.1038/nn.3085

Zempi, I. (2017). Researching victimisation using auto-ethnography: Wearing the Muslim veil in public. *Methodological Innovations*, 10(1), 205979911772061.  
doi:10.1177/2059799117720617

Zlatev, J., Racine, T. P., Sinha, C., & Itkonen, E. (2008). 1. Intersubjectivity: What makes us human? *The Shared Mind*, 1-14. doi:10.1075/celcr.12.02zla

Zweig, Y. R., & Galvin, J. E. (2014). Lewy body dementia: the impact on patients and caregivers. *Alzheimer's Research & Therapy*, 6(2), 21. doi:10.1186/alzrt251

## Appendix 1

*Example of highlighted extracts across meta-ethnography's selected studies.*

*Kalis et al (2005) Ideals regarding a good life for nursing home residents with dementia: views of professional caregivers – (1)*

Caregivers try to create a warm, safe home on the wards by preventing occurrences of agitation and other disturbances.

Putting an arm around someone or ... well, just showing attention like: who are you, what did you go through, what do you experience, what do you encounter, what do you find difficult, what do you really like?

In the interviews, the three most prominent concepts ('peace and quiet', 'going along with subjective experience' and 'no enforcement: the way the resident wants it') all emphasize the importance of subjective well-being as opposed to more objective values

daily caregivers tend to be less concerned with objective ideals and are primarily concerned with promoting pleasant experiences for residents, whereby the content of those experiences is seen as a purely subjective issue.

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*Kelly (2008)- Forgetting and the memory of forgetting – (2)*

the capacity for recalling and sharing memories and memory loss are of intersubjective importance and are not simply the result of the absence or presence of disease.

Memory is central to the way people construct an identity and their life story, not in isolation but in relationship with others.

Not only do people remember the serious aspects of their lives in order to create an identity and relationship with others, but also they recall fun moments and play with memories to arouse a response in others and share humour.

He became anxious in anticipation of such an irrevocable loss, of not having a sense of others in relationship to himself. He also feared the loss of speech: not only the loss of neurological skill, but also the capacity to engage intersubjectively.

*Svanstrom et al (2013) – Suffering caused by care—elderly patients’ experiences in community care – (3)*

Loneliness became obvious. This feeling tended to contribute to a passive life. For the person with dementia who lives alone... This gives a picture of a passive home-care organization that did not really recognize basic human needs.

An absence of dialogues... It was rather that the dialogue occurred in the moment, when the caregiver was open to a positive meeting; or, as Arnold described the situation, “They joke with me to make me happy

Performing tasks together in a dialogue can anchor the patient in a context, in the everyday world.

The consequences of an absent dialogue become obvious: the patient’s basic care need does not become fulfilled.

Human dialogue includes both speech and intersubjectivity where both interlocutors see the other’s face.

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*Ullan et al (2013) – Contributions of an artistic educational program for older people with early dementia: An exploratory qualitative study – (4)*

The participants’ positive experience of learning new things (‘it’s always good to learn things in life’; ‘it’s always good to learn’; ‘I didn’t expect to learn’; ‘I have really enjoyed it, each day we learned something’

The skills of people living with dementia are frequently underestimated, emphasizing their deficits and, consequently, they are faced with tasks of a low level of intellectual stimulation or sense of achievement.

The fear of being negatively stereotyped, their capacity to develop the cognitive skills that are still intact, their capacity to meet the demands of daily life, their quality of life, and their capacity to lead a meaningful life.

The effect on communication and social relations... Communication processes with the participants, as it led to establishing spontaneous conversations with them about various topics, many of them related to these people’s vital experience.

Participants with dementia in the cultural and learning activities and their capacity to engage in them and to enjoy the experience.

To empathize with the subjective experiences of people living with dementia, and recognize the importance of intersubjectivity and relational aspects

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Boyle & Warren (2015) *Showing how they feel: the emotional reflexivity of people living with dementia* - (5)

Rather than being deemed a loss of rationality, emotions in dementia can be viewed as an experiential process of reasoning through the impact of the illness on one's sense of self and relations with others. Therefore, the emotion of people living with dementia demonstrates reflexivity.

Rather than their emotions being indicative of disordered minds, they highlight when they are trying to make sense of their shifting social worlds.

Yet, since emotional experiences are 'co-created' (Wetherell, 2012), negative emotions can reflect how relational agency relies on the provision of social support – practical and emotional – which may not always be forthcoming or adequate.

Relational dialogue is the means by which we take account of our own and other people's values and make moral judgements about our actions.

Potential capacity for reflexivity in people living with dementia being overlooked.

Grace was very critical and disparaging of herself – frequently apologising to us for her perceived limitations

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Johnson (2016) – *Exploring the Lived Experience of People living with dementia through Interpretative Phenomenological Analysis* – (6)

In the first interview, my interview questions focused on participants' interests, activities and Identities

...Alzheimer's disease maintain a sense of personal identity, but often experience threats to their subjectivity and public presentation of self when those around them restrict their autonomy, silence their voice and persist in defining their behaviour as symptomatic of dementia.

Focusing on these themes allows me to present a detailed exploration of the ways in which participants construct their identities, and of the key role of intersubjectivity within this.

The support and company of others were valued highly by all of the participants. Some participants felt that they had been rejected by others because of their dementia

Social support and relationships were very important to participants, and much of their talk focused on this. The companionship of friends and family was a source of happiness

It was common for participants to associate dementia with stupidity or irrationality, and to worry that they might be labelled in this way themselves.

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Boyle (2017) – Revealing gendered identity and agency in dementia (7)

... it is clear that people living with the condition view themselves intersubjectively.

They retain a perceptive understanding of the dynamics of intimate relationships and endeavour to remain involved in family and community life.

The dialogue of women and men revealed their own voices and echoed the voices of tangible

Viewing reflexivity as a socio-emotional (rather than a cognitive) process enables the agency of cognitively disabled people to be more readily recognised.

It was notable that people living with dementia often expressed their agency in embodied and emotional forms, including via humour. Thus, broadening our understanding of what constitutes communication and 'dialogue' would help to facilitate the gendered voices of people living with this condition and promote their relational agency.

Three women with dementia bemoaned the pastimes they shared with their husbands—notably masculine sports—when they would have preferred to engage in other social activities

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Marsh et al (2018) – *The landscape of dementia inclusivity* (8)

Meaningful connections that enhance community knowledges, understandings and acceptance of people living with the impacts of dementia

Our findings demonstrate that being outdoors – among nature, plants, gardens and birds – appears to encourage participants to interact with each other in ways that reduce hierarchical boundaries.

Relationships between participants were characterised by a willingness to be respectful and by intentions to include and be included

This is best exemplified by the comments from volunteers who stated they assumed the conversations they were having were about current realities, not memories.

The story was about the present or the past. These types of encounters are respectful of the personhood of people living with the impacts of dementia.

Recognised therapeutic features of community gardening include heightened self-worth, sense of achievement and social attachments

<b>COLOUR INDEX</b>	
	<b>Activity in dementia</b>
	<b>Relationships in dementia</b>
	<b>Connecting with people and personhood in dementia</b>
	<b>Communication in dementia</b>
	<b>Reflexivity in dementia</b>

## Appendix 2

*Updated (New Title) Ethics letter*



Applicant: Gary Hodge  
Supervisor: Mark Limmer  
Department: Health Research  
FHMREC Reference: FHMREC19011

03 October 2019

Dear Gary

**Re: Becoming Intersubjective 'in medias res' of Behaviours that Challenge in Dementia: A Layered Autoethnography.**

Thank you for submitting your research ethics amendment application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987

Email:- [fhmresearchsupport@lancaster.ac.uk](mailto:fhmresearchsupport@lancaster.ac.uk)

Yours sincerely,

A handwritten signature in black ink that reads "R.E. Case".

Becky Case  
Research Ethics Officer, Secretary to FHMREC.