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# **University of Southampton**

Faculty of Environmental and Life Sciences

School of Health Sciences

**Stories of (im)mobility: people with dementia on an acute medical unit**

By

**Pippa Collins**

**BSc; MRes; MCSP**

Thesis for the degree of Doctorate of Philosophy

April 2020



# University of Southampton

## Abstract

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Stories of (im)mobility: people affected by dementia on an acute medical unit

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Through a lens of mobility, this thesis explores the narratives that people with dementia shared when they were inpatients on an acute medical unit.

It is well documented that care for people with dementia when they become patients in an acute hospital is not good enough, with people losing mobility and independence skills. Despite this, there is a virtual absence of the voices of people with dementia in acute hospital research. When people have been included they have been positioned within the research as recipients of care, rather than people in their own right.

This narrative enquiry is underpinned by the model of social citizenship that recognises people with dementia as citizens with voices. The study did not rely on researcher led questioning to elicit narratives, instead focusing on spontaneously produced conversations that were either video or audio recorded. Several narratives were also recorded in field notes. This enabled each participant to share what was important to them in that moment of time.

The study findings were both empirical and methodological and showed that people with dementia have narratives to share, but these narratives do not fit the bio-medically constructed model that is generally expected from patients. Utilising a mobilities lens enabled the narratives to be understood as containing layers of communication. The first layer is the words; the second layer is gestures and movements that support the words; and the third layer is micro movements. These movements do not only support the words but in some cases tell a different story altogether.

Attention to the layers of communication reveal personhood as a mobile process that requires work from both the teller and the listener to maintain. The micro movements are shown to be the physical manifestations of embodied language. I argue that viewing personhood through a mobilities lens is important to the advancement of dementia and citizenship practices.



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## Research Thesis: Declaration of Authorship

Print name: Pippa Collins

Title of thesis: Stories of (im)mobility: people affected by dementia on an acute medical unit

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before.

Signature: ..... Date: 7 October 2020



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# Chapter 1 Narratives of movement and micro movement

*“We will listen most carefully to those whose voices are weakest and find it hardest to speak for themselves.”* (The Mid Staffordshire NHS Foundation Trust Public Enquiry 2013)

I see Lena at home on a baking hot August afternoon. Lena is dying. Her husband is beside her on this journey – the man who knows her better than anyone else. The curtains are pulled against the heat and light, leaving the room in cool pastel shade. A mower drones outside. Within this life of striving some of us are gently leaving. I sit stroking her hands and face; soft skin and huge blue eyes which followed the conversation. She pulls me down towards her, strokes my hair and kisses my cheek. No longer with words her gaze moves from me to him. I bend and kiss her cheek as I leave. He says she’s not usually like that with people who come in and I feel deeply honoured and terribly sad at the same time.

And I wonder now at our inability to let silence grow between us and why the socially acceptable norm is to fill that space with words, questions, demands and expectations. And sometimes how silence, touch and small movements can say so much. I wondered at the stillness of Lena and how she could communicate so much with no words and so little movement.

## 1.1 Introduction

This Clinical Doctoral thesis aims to explore what narratives are shared by people with dementia when they become inpatients on an acute medical unit (AMU). The particular interest of this study is how and why narratives are shared by people when they become inpatients. These narratives are viewed through a lens of mobility that takes into consideration both macro and micro movements. Macro movement here is considered to be the movement of people, objects and equipment within the hospital; micro movements are considered as the small, subtle, embodied movements that people make, often unconsciously, when telling a story.

This study is based within a hospital in the south of England within which I worked as a National Health Service (NHS) physiotherapist. This necessarily means that the focus of this thesis is on practices that are found within the NHS. However, as the thesis focuses on the processes of narrative, I hope that the findings have applicability across national boundaries.

This chapter aims to provide explanation of why I have undertaken this study, and an orientation to the structure and content of the thesis, including the research questions that underpin it.

## 1.2 Noticing immobility and movement

Mobility is not only physical movements both big and small but also the movement of people, goods, equipment, ideas, money and intellect (Cresswell 2006). Mobility is everywhere. Yet when I looked around the acute medical unit AMU I saw older patients with dementia who often did not appear to be moving; points of stillness surrounded by mobile and noisy healthcare professionals.

I observed that people with dementia were restricted to their bed space and often restricted to their beds. People were given limited opportunities to engage in personal care tasks, and on several occasions I noticed people with dementia deteriorating physically and mentally over the short period of time that they were on the unit. I observed that when a person with dementia had 1:1 care this often entailed attempts to restrict their mobility. There was a "Sit down, Mrs Jones" mind set.

I decided to study this juxtaposition of the seemingly immobile patient and the mobile professional through a consideration of the narratives that people shared during an admission, and to answer the many questions that I was starting to ask. Why and what do people tell us? What do these narratives reveal about the person? Can an exploration of these narratives help us to understand the person? And does a focus on mobility help in this understanding?

This study evolved from my experiences working as a physiotherapist on an AMU, where I saw people with cognitive problems on a daily basis and often they appeared unhappy, distressed and anxious. Sometimes I stood still and looked and listened to what was going on – twenty three people around the nurse's station; two people passing by; three conversations on phones; IV pumps alarming and other patients talking or calling out. I remember how chaotic and mad I thought the place was when I arrived, and I felt well and understood the meaning of much going on around me. Unlike the older patients with dementia, I could also leave the unit when I wanted to.

Prior to the start of this study I met with people who have dementia, and people who were friends or relatives of someone with dementia, through our Doctoral Training Centre<sup>1</sup> public engagement group. I also talked to patients and relatives in the hospital, spoke with people at Dementia conferences and events that I attended, and people that I met socially. At each encounter I asked if the topic that I was proposing to study seemed worthwhile. Again and again I came across people who were terrified of hospital admission because they had seen people

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<sup>1</sup> The Doctoral Training Centre provides training for Doctoral Research Fellows and is funded by the Alzheimer's Society

deteriorate physically and cognitively whilst an inpatient. One lady told me: “it is our most major fear; everyday it’s our major fear. Tom had an infection about a year ago and I just went into overdrive I was so worried; people we meet have life changing experiences. When their other half comes out of hospital, they have gone down the slope”. I met patients and relatives who told me of lost independence, lost clothes, lost continence, lost hearing aids and glasses. I also heard about exceptional care where staff had made a huge difference. One thing that all people had in common was the belief that more needed to be known about what it is really like for someone with dementia to be an inpatient.

I wanted to explore these subjective impressions from the perspective of someone actually going through the experience, and to use research evidence to change the way that people with dementia are understood in this busy environment, where everyone works under pressures of time.

During this time I became aware of the social citizenship movement within dementia (Bartlett and O’Connor 2010). Social citizenship positions people with dementia as citizens with rights, and citizens with voices. I recognised that the conceptual model of dementia that is in use within UK healthcare is based upon Kitwood’s (1993) model of personhood and person centred care, and that this places the person as a passive recipient of care, rather than as an active agent (Bartlett and O’Connor 2010). This recognition had a profound effect on my clinical, academic and personal understandings and became central to the planning of this thesis, as I recognised that I too, was positioning people as part of the cared for/carer dyad. I wanted to design my research in a way that was inclusionary and not exclusionary, and which enabled each participant to be considered as an individual with a unique narrative to share, and not simply as a person receiving care.

This study focuses on both spoken and embodied narratives. Current research in which people living with dementia are involved has utilised interviews with people who are verbally fluent; or interpretation of behavioural observations. This is discussed further in Chapter 2. In this study I explore the narratives of people who do not verbalise in a contextual and temporal way, and also utilise body and facial movements to communicate their narrative to the people around them, through what I term micro movements. My clinical experience is that health professionals find interpretation of this form of communication difficult, and people are often labelled as “confused” and not listened to. Clinically I observe that professionals do not seem to understand that people with dementia can communicate, but that they communicate differently and often communicate things that we are not expecting.

### **1.3 What is mobility?**

“Mobility is life itself” (Cresswell 2006).

At the start of this study, I understood mobility in the acute hospital context as the ability of a patient to move around as they wish, to participate to their normal level in functional activities and to remain as independent as normal. However, my exploration of the literature around independence and mobility reflected and explained what I was seeing in practice: people with dementia on the AMU are not moving. This created a problem for me.

As time has gone on I have consistently questioned whether to drop “mobility” from the heart of my research because “there is no mobility on the AMU”. However, it became increasingly apparent to me that my definition of mobility was too narrow and reliant on a normative concept of physical movement of the body. This realisation has led me to ask “what is mobility?”

The hospital is constantly on the move. Movement fills our entire working time, no matter in what kind of work we are engaged (Cresswell 2006). Movement becomes an asset that those of us who are empowered use without thinking. The same physical journey means different things to different people. I walk from the emergency department to the acute medical unit to assess a patient or liaise with my colleagues; the same journey is done by a person on a trolley, unwell, in pain, disorientated in the middle of the night. Older patients in particular lie immobile on their beds, have no control; do not know where they are going and are perhaps anxious and fearful. Yet there is mobility all around on the AMU. People with dementia sit or lie in stillness; watching and listening to the constant motion and noise. It occurs to me that mobility is another form of discrimination along with age; those of us deemed able, can come and go as we please. The ability to move around the hospital freely, or not, carries with it an imbalance of power.

It was not until I started to analyse the narratives that had been shared with me that I started to recognise that mobility is also a form of communication and that it is all around us. I began to wonder if by bringing attention to movement as communication, insights could be gained into people with dementia whilst they are inpatients.

### **1.4 The research questions**

This is a narrative enquiry, the central aim of which is to further our understandings of people with dementia whilst they are on an AMU through, an exploration of their narratives. The study sets out to answer the following research questions:

1. *What narratives are shared by a person with moderate or severe dementia in social or medical crisis when they are an inpatient on an acute medical unit?*
2. *Does a mobilities lens help in the understanding and interpretation of these narrative?*
3. *How can people with moderate or severe symptoms of dementia be enabled to contribute to the research agenda on acute hospitals?*

In order to establish the theoretical orientation and empirical relevance of the study, I needed to undertake a review of the literature. As my initial focus was on mobility for people with dementia in an acute hospital, this was my first systematic search (Appendix A) the findings from which informed both Chapters Two and Three. This search made it apparent that there is a paucity of literature that focuses solely on people with dementia, and also helped me to recognise that I was interested in how acute care was experienced, and not only in mobility.

Consequently, I widened my search criteria and altered my focus. This new search was part of a wider, published systematic review that I was involved with (Appendix B), which focused on the acute hospital experiences of older people in general. My role, with one other author, was to design the search criteria, run the searches, and play a substantial part in screening and analysing the results. Within this, a subset of the papers focused on older people with dementia, and these became the basis for Chapter Two which considers the care of people with dementia in acute hospitals.

I also recognised that I needed to review the literature around narratives and embodied language. The nature of this topic is that it is discussed in a very discursive way in books and book chapters, some of which I would not have discovered through traditional searches of databases. It was, therefore important for me to manually search citations of, and references from, key texts, such as Pia Kontos' work on embodiment and dementia. I also read widely from the qualitative literature around narrative enquiry, and followed up on references and that I came across there.

## **1.5 Structure of the thesis**

Chapters Two, Three and Four set the context within which this study is set. Chapter Two discusses the care of people with dementia in acute hospitals and how a focus on safety and risk aversion has led to older people in general, and people with dementia in particular, experiencing care that is not good enough. The chapter goes on to consider person centred care and whether this is achievable in acute hospitals, before moving on to consider a social citizenship model of dementia and the EXPECT research agenda (Bartlett and O'Connor 2010). The chapter concludes by considering the absence of voices of people with dementia in acute hospitals.

## Chapter 1

Chapter Three questions the definition of mobility and explores the mobility and immobility dynamic within the context of acute hospitals. With reference to current research literature the chapter illustrates how people with dementia are not enabled to be mobile or independent; and that this can cause the person to be more cognitively and physically dependent at discharge.

Chapter Four considers narratives within the context of the acute hospital environment and asks whose story is being told. This chapter introduces embodied language whereby the body is an important means by which people engage with the world, and express their understanding (Kontos 2005).

The overall aim of these chapters is to establish the theoretical orientation and empirical relevance of the topic, and to highlight the current gaps in knowledge that this thesis aims to address.

Chapter Five describes the methodological context for this study and the qualitative methods that were used to collect and analyse data. This chapter also considers the processes of gaining consent and recruitment, both of which aimed to be inclusionary rather than exclusionary. The participants are introduced in this chapter.

Chapter Six presents my first impressions of the data and starts to address the first research question. Chapter Seven continues to respond to the first research question. This chapter also addresses the second question by undertaking a deeper analysis of the narratives through an exploration of the embodied language that is portrayed by the participant's movements and micro movements.

Chapter Eight utilises the heuristic device of the EXPECT agenda (Bartlett and O'Connor 2010) to consider the findings and to address the third research question. Chapter Nine is a reflective chapter that considers how the thesis in itself is also a narrative of my journey from physiotherapist to PhD researcher.

## Chapter 2 People with dementia in acute hospitals

### 2.1 Overview

This chapter considers the care of people with dementia in acute hospitals. The central aim of this chapter is to critically review how people with a dementia diagnosis are cared for in an acute hospital. The chapter presents a general overview of care for this patient group; considers the use of person centred care within acute hospitals; goes on to consider risk and the construction of risk and how this can impact on mobility; and finishes with a consideration of a social citizenship and right based approach to dementia.

I contend that the dementia narrative in hospitals is created about and not by the person, and that this leads to people with dementia being viewed negatively, marginalised and left immobile. I also critique the literature in order to ask what narratives are in play; and to discover if there are any empowering or positive voices within acute care that are authentically the voice of the person with dementia.

### 2.2 Care in acute hospitals

The prevalence of people living with dementia among general hospital inpatients has been surprisingly little studied and estimates vary depending on the type of inpatient setting (World Alzheimer's Report 2016). In the UK up to 42% of people aged over 70 who have an unplanned hospital admission have dementia (Royal College of Psychiatrists [RCP] 2019), and overall people with dementia are estimated to make up a quarter of the inpatient hospital population at any one time (Public Health England 2015; Prince et al 2016; RCP 2017). However, whatever the actual number of people with dementia is in hospitals generally, staff report surprise or even shock on entering their professions, at the large proportion of older patients with cognitive impairments (Gladman et al 2012).

Although the money currently being spent on acute dementia care is considerable, it is being used to provide a service that does not meet its user needs adequately (Briggs et al 2017). All individuals with frailty, whether that is physical, cognitive or both, who are discharged from hospital even after a short admission of less than 72 hours, experience increased mortality and resource use (Keeble et al 2019).

People with dementia often face difficulties when in hospital, including increased confusion and disorientation, length of stays longer than people without dementia, potentially avoidable

## Chapter 2

complications such as dehydration or falls, and delays when leaving hospital (RCP 2019). Research evidence shows that the pace and noise of the acute medical environment is difficult for people with dementia, and poor experiences in these areas can affect patients for the remainder of their hospital journey producing a profound and permanent effect on them (Alzheimer's Society 2009; The Royal College of Nursing [RCN] 2013; Dewing and Dijk 2016).

The Alzheimer's Society report (2016) "Fix dementia care: Hospitals" showed that on average people with dementia stayed twice as long in hospital than other patients over the age of 65 and that the longer people with dementia are in hospital, the worse the effect on their dementia symptoms and their physical health. Hospital stays led to weight loss, incontinence, exhaustion, pressure sores, bruising, reduced mobility, loss of communication skills and depression. Furthermore, 92% of the Alzheimer's Society survey respondents reported that hospital environments are frightening for a person with dementia. The longer length of stay and associated decline in mobility and cognitive skills led to 36% of people who were admitted from their home being discharged to residential care. Additionally, in another survey of acute hospital care (RCP 2017), only 1% of carers said that enough help with personal care was provided, 1% said help was given with food and drinks and 1% said that stimulation or activities were available. It is hard to imagine any other patient group where these outcomes would be tolerated.

Recognition that dementia care in the UK needs improving has led to a succession of national strategies under successive governments. The National Dementia Strategy (Department of Health [DH] 2009) was published under the then Labour government and aimed to ensure that dementia services were improved across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. Improved quality of care for people with dementia in general hospitals was a specific priority. Following a change of government the Prime Minister's Challenge on Dementia (DH 2012) was published under a Conservative and Liberal Democrat coalition which incentivised improvements in care by offering financial rewards for hospitals providing good quality care. The government again changed and the Prime Minister's Challenge on Dementia 2020 was published in 2015 with the aspiration to provide high quality, compassionate care with timely discharges; and a high emphasis on dementia research and the education of the healthcare workforce. However, despite this focus on improving care, the Progress Report on the Prime Minister's challenge 2020 (Department of Health and Social Care 2019) found that people with dementia were still experiencing hospital care that fell short of the 2020 ambitions, for example the nutritional needs of people with dementia are not being met and people are not being assessed for delirium.

The detrimental effects on the symptoms of dementia and physical health that can occur during hospitalisation can lead to an increase in dependency at discharge which Lafont et al (2011) described as “iatrogenic disability”. Iatrogenic disability is the effects of avoidable dependence in activities of daily living that can be induced during a hospital admission. The people most at risk are those with advanced age, cognitive impairment and dependence in activities of daily living prior to admission (Lafont et al 2011). Having a diagnosis of dementia also increases the likelihood that a person is admitted to hospital, as many people with dementia have frailty and complex medical comorbidities, making their hospital admission rate higher than for similarly aged people (Phelan et al 2012; Prince et al 2016). Overall risk of developing iatrogenic disability is thus increased for this group.

Within the context of acute hospitals iatrogenic disability can start to be explained by understanding the model upon which care is based. The physical environment, working practices and care processes of acute hospitals are geared to the model of acute medical care that presupposes that the main task of the hospital is treatment and cure. This model is reliant upon care pathways and performance targets which can actively obstruct the delivery of high-quality care for patients with complex conditions such as those with dementia (Cornwell 2012).

The treatment and cure model is reliant on the fast flow of patients through and out of the hospital. Care processes prioritise those activities which have an immediate effect on discharges such as medication rounds and managing acute illness (Bail and Grealish 2016) which then frees up a bed for an incoming patient and increases “patient flow”. This creates a fast-paced atmosphere with a corresponding demand for quick solutions which hospital employees refer to in such terms as “fast and furious”, “tug of war” and “gatling gun” approaches (Parke and Chappell 2010 p119). Those who have a poor short term memory or have difficulty following directions require more attention and therefore take time away from more acute patients who are deemed as the priority. These patients are de-prioritised and their care is effectively rationed by nurses who prioritise other patient groups (Bail and Grealish 2016).

Bail and Grealish (2016) proposed a theoretical construct of “failure to maintain” which describes how care rationing by nurses, who are working to meet the demands of a fast paced environment, contributes to functional and cognitive declines during hospitalisation. With specific reference to people with dementia, nurses acknowledged that they neglect basic care needs such as mobility and taking a person to the toilet because these personal care tasks are time consuming and unpredictable (Bail and Grealish 2016). Paradoxically when these activities are not carried out they can increase a patient’s length of stay and increase the risk of hospital acquired complications, which decreases patient flow. Thus processes are designed around the movement

## Chapter 2

of patients through and out of the system (patient flow), but it is the personal characteristics of the individual patient, such as having dementia or not, that can make all the difference between positive or negative admission experiences (Parke and Chappell 2010).

Iatrogenic disability is further compounded by a privileging of risks such as falling, which has led to a nursing perception that mobility for older people is a threat to their safety (Dahlke et al 2019). This risk is managed primarily through the use of physical restraints and limiting mobility (Digby et al 2017; Featherstone et al 2018; Dahlke et al 2019) and the delivery of routine physical care in a functional manner with little personal engagement (Cowdell 2010). The unintended consequence of these constraints is a functional decline that takes place over a number of days and is thus less visible to an individual nurse on a shift (Dahlke et al 2019). There is not an immediately obvious relationship between action (limiting mobility) and outcome (increased dependence) which is thus less well recognised than such risks as falling over or developing a pressure ulcer.

Hospitals are still struggling to acknowledge that the largest group of users are the very old, those with frailty and the dependent (Tadd et al 2011) whose needs take time to fulfil, and for whom communication is not always straightforward or easy. The physical environments of acute hospitals have not been designed for the requirements of people with cognitive impairments and hospitals can be frightening to a person with dementia (Alzheimer's Society 2016). Care environments should promote independence, well-being and patient safety, with patient input to ensure standards are met (RCP 2019). Although there has been a significant increase in the number of hospitals reviewing their environments for people with dementia (RCP 2019) many wards still offer unfamiliar and clinical environments which are busy, noisy and lack space. This impedes effective communication; there is little opportunity for engagement in meaningful activities; and at night dim lighting and low staff levels can cause disorientation (Gladman et al 2012). Such hospital environments can prevent nurses from having opportunities to critically think about activities they could engage in to mitigate the functional decline of older patients because they are constantly looking for strategies to keep their patients safe (Dahlke et al 2019).

Clarke (2000) argues that the physical and interpersonal care environments for people with dementia are manifestations of a medico-biological construction of risk where perceived needs can be met, and risks to self and others minimised by the use of set protocols. The core belief is that managing what goes into the system will have a direct and measurable effect on what comes out of the system.

However, in a complex hospital system in which multiple people care for complex patients, this simplistic causal model is inaccurate. These perceived risks have implications for the safety and

the independence of the individual, but they also have implications for the accountability of the care providers, perhaps for friends and family and for wider society (Faulkner 2012).

Thus the concepts of risk and risk reduction have an impact on all players in the scene.

### **2.3 A focus on safety**

Perceptions of risk and measurement of risk are highly influential on the way that care is delivered in acute hospitals and can have unintended consequences for the person with dementia. The definition of risk is “the probability that a particular adverse event occurs during a stated period of time, or results from a particular challenge” (Heyman 2013 p615). Risk management within acute hospitals therefore involves the identification of potential adverse events and plans to avoid them happening. However, “risk” is increasingly being seen as synonymous with “danger”; and these dangers are dependent for identification on the cultural context in which they are located (Douglas 2002).

The cultural context of acute hospitals has led to the identification of physical harms, such as falling over, pressure ulcers or infections as those which are prioritised. There are other risks though, such as damage to a person’s self-esteem or independence, that can be caused when older people are encouraged to remain in bed, or in chairs beside their bed and to use bed pans, commodes or continence pads rather than be helped to access the toilet (Tadd et al 2011). For a person with dementia this imposed immobility can pose the additional risk of cognitive deskilling. However, as Tadd et al (2011) suggest within healthcare what matters is what is measured. It becomes unsurprising, when considering the risk management imperatives of acute hospitals that one of the effects of an inpatient stay for a person with dementia is iatrogenic disability and an increase in dependency at discharge (Alzheimer’s Society 2009).

Viewed from this perspective, the decline in independence that is often the result of an acute admission can be understood to be due to the discrepancy between what events the organisation considers to be “adverse”, and what is adverse to the patient. Trust priorities are set by measurable performance indicators (such as number of falls), a culture of blame and high bed occupancy necessitating frequent bed and ward moves (Tadd et al 2011). This culture makes it difficult for the needs of the patient to be foregrounded by ward staff and can lead to restraint rather than enablement (Featherstone et al 2018), causing dependency and deskilling.

When risk management and performance indicators become the focus of the professional due to institutional targets, then the unintentional effect of “priming” can occur, whereby the use of the word “risk” primes thoughts of risks and the individual’s cultural biases and values are triggered

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(Ng and Rayner 2010). An overly cautious approach to risk then ensues. The person with a dementia diagnosis is surrounded by the language of risk from relatives and hospital staff, whereby they need to be “safe and looked after” and fears are raised that the “encouragement of independence always results in increased risk to the individual” (Clarke et al 2009 p92). The argument around risk therefore gains a degree of circularity, the risks that are identified become the *raison d’être* for behaviours of staff, certain risks are measured and these risks are looked for, found, managed and quantified.

Thus, fore fronting physical risks for the patient, such as falling over, can cause frontline staff to be afraid of being held responsible should something happen “on their watch”; members of staff will often act defensively, and may themselves feel disempowered in a situation that does not support them to take risks with and for their patients (Faulkner 2012). Staff are effectively disempowered by the culture of risk and blame, and default to a position of restraint and restriction of people with dementia (Featherstone et al 2018) in order to prevent perceived harm and avoid being blamed.

The dangers that are identified clinically, and are therefore measured and monitored by hospitals are unarguably important and their occurrences need to be minimised. However, there are other risks for people with dementia such as delirium, longer length of stay, and institutionalisation at discharge (Fogg et al 2018). There is also the risk of preventing a person from being independent and taking risks that any one might take on an average day (Faulkner 2012) thus deskilling them in daily living skills.

The focus on reducing measurable clinical risks can lead to unintended consequences for the patient with dementia. The Quality Account Summary for the hospital within which this study takes place focused for the last two reporting periods prior to this study, on reducing pressure ulcers and high harm falls. This focus has resulted in a 20% reduction in incidences of both; an achievement that should rightly be applauded.

However, in the last year, the health care professionals have recognised that patients are remaining in bed, are losing mobility and function and for older people and those with dementia particularly, are being discharged with a greater degree of dependence than pre-admission (Lim et al 2018). Although this situation is recognised at the ward level, it is not included as a measured harm by the hospital and is therefore not considered an institutional priority. Neither is an association between the two made (personal observation). The reduction in the incidence of pressure ulcers is due in a large part to the introduction of the “turnaround chart” whereby a person is turned in bed every two hours, or sat in a chair for two hours. Standing and walking, the most effective forms of pressure relief are not included; and when time is limited it is quicker to

turn someone in bed than to help them into a chair, or to walk or stand. People who require assistance to mobilise remain in bed; remaining in bed also reduces the chances that someone will fall over. Additionally the turnaround chart is time dependent resulting in people being returned to bed just as their meal arrives causing additional risks to their nutritional intake.

Risk is a construction and will only be so recognised if its outcomes matter to a particular social group, and reducing one type of risk can lead to unanticipated and unwanted effects (Heyman et al 2012) such as those outlined above. However, if these unanticipated effects are not measured and reported by the hospital then they will remain unrecognised and unaddressed. The narrative of the professional is privileged over that of the patient and relative, and this fore fronting of the technical evidence base enhances the technical competence of the professional, but does not necessarily lead to decisions that are sensitive to the individual person (Alaszewski et al 1998).

## **2.4 Risks for the person**

The construction of risk is often constrained by a rationalist perspective that focuses on physical causes and outcome, and that presents risk as external to the self and predictable (Ballinger and Payne 2002). In acute hospitals events that are considered to be adverse and their risk of occurrence minimised is decided by senior clinicians; and policies and procedures to minimise the risk of these events occurring are developed. This focus on creating certainty around risk management and keeping the person safe, rather than building the skills to manage uncertainty, places the person with dementia in a position of being deskilled and increasingly dependent on service provision (Clarke et al 2009).

Within the context of a UK day hospital, Ballinger and Payne (2002) found that the service providers' discourse focused on physical safety and the wellbeing of the older people who attended the day hospital. Prevention of falling over was prioritised, however the service users found that the restrictive measures used created risks to their personal identities of independence and general capability. For community dwelling older people, whereas physical risks such as the risk of falling were emphasised by professionals, people with dementia prioritised psychosocial domains of risk such as loss of identity and lifestyle; and loss of self-esteem due to increased dependence (Yardley et al 2006).

From the perspective of a person with dementia there are additional risks created by being an inpatient on a hospital ward. Admission can represent a "core problem" of disruption from normal routines; and a "core process" whereby an attempt is made to gain control of this disruption (Clissett et al 2013). This disruption to routine causes distress which the person may attempt to address with either constructive, disengaged, distressed or neutral behaviours (Porock

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et al 2015) all of which are a form of communication but are not interpreted as such. There is no time or space to offer emotional comfort, alleviation of distress or for building relationships; and health professionals are poorly trained in these skills (Harwood et al 2018).

Attempts to regain control of one's life can take the form of resistance to care processes which staff respond to with containment and restraint (Featherstone et al 2018) rather than with recognition that this is a form of communication from a person who is responding to a significant disruption in their life. Additionally, interactions between patients and staff that are dominated by ward routine and the delivery of essential physical care do not allow time or enable a person to participate in personal care activities in their normal ways, leading to care being delivered in an impersonal manner (Cowdell 2010).

People are at risk of further disorientation and upset because in many instances they are dependent on interactions with people around them for "sense-making" and "self-making" (Hydén 2018 p73). The way that someone understands their current situation, as well as their identity within this situation, is dependent on others confirming and acting in a supportive way. A disruption in the relations between the person, the environment and the current tasks can lead to a "catastrophic reaction" (Hydén 2018), which can manifest as agitation or withdrawal for example.

In the UK there has been an acknowledgement that current care practices can lead to the risk of harms that are not just physical. The "Nothing ventured, nothing gained: risk guidance for people with dementia" (Department of Health [DH] 2010) presents guidance on how to manage risk in a positive way that respects people's rights to take risks, whilst also keeping them safe. This guidance recognises that the biggest barriers to enabling people with dementia to have more control over their lives is an overly cautious approach to risk, and that 'safety first' approaches are disempowering for people with dementia.

Following on from this guidance, the RCN (2017) have recognised that the challenge for health care professionals is to positively manage risk and deliver care, whilst navigating the complex legal and ethical processes which must guide practice. They recommend embedding the delivery of care, treatment and services in a rights based approach, which places the person at the centre; and recognise that current nursing practices can lead to risks that are not only physical. The RCN report recognises that there is a lack of a shared understanding that practices such as the use of bed rails and attempts to restrict free movement on a ward are restrictive. Professionals who routinely implement such practices do not always realise that these are restrictive and very possibly unlawful.

The RCN (2017) report provides guidance on the least restrictive options available to keep someone safe. This advice recommends that a multidisciplinary team discussion must take place which includes the person and their representative. Consideration must be given to whether the way that care is delivered may limit the person's movement, daily activity or function; result in the loss of objects or activities that the person values; or require the person to engage in a behaviour that they would not engage in given freedom of choice. The RCN report represents a clear move towards a rights based approach towards the provision of care. For people with dementia this may be the first step towards recognising their rights as citizens within the acute hospital system. However, if members of the multidisciplinary team are not skilled in communicating with someone with dementia, then there is a risk that understanding their needs and protecting their rights becomes impossible.

Decisions around which risks to recognise and manage are made by a particular social group. As "decisions must somehow be made, the calculation of expected value on the basis of available evidence may offer the best practical guide to collective and individual risk management decision-making" (Heyman et al 2012). This leads to the following questions: If this available evidence is one sided and only considers the values of the institution within which the risk is located, and does not include the perspectives of others, can these decisions be made with any degree of confidence?

In contrast to the findings from the research discussed above is person centred care. Person-centred care focuses care on the needs of the person rather than the needs of the service (RCN 2019) and is personalised, coordinated and enabling, where the person is treated with dignity, compassion and respect (The Health Foundation 2016). Implementation of person centred care has been a core aspiration for the provision of good care for older people in the NHS since publication of the National Service Framework (DH 2001) and yet research evidence shows time and again that the requirements of individuals who do not fit the acute hospital model of care are subsumed by the institutional priorities of the hospital (Bail and Grealish 2016).

## **2.5 Person centred care – Is it possible?**

The philosophical underpinnings of care for older people with dementia are currently based on the concept of personhood. This concept considers the desire for self-definition (Who am I?), the answer to which leads into the moral consideration of "how am I to treat others and be treated by others?" (Phinney et al 2007 p174). Although personhood is a philosophically debated concept, it was used by Kitwood (1997) to underpin his model of "person-centred" care which he used to

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contest the dehumanising treatment of people with dementia that he had witnessed in institutional care settings. He defined personhood:

*“It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of, and the failure to do so, have consequences that are empirically testable”.* (p8)

Kitwood recognised that in a society where cognitive ability is valued and accepted as an essential part of being a person, having cognitive problems can lead to a person being positioned as a non-person. This, he believed, could be due to unconscious anxieties in others around becoming dependent, older and vulnerable themselves. He argued that this position then becomes a perfect rationalisation for uncaring attitudes because where personhood is widely disregarded, those who are powerless are liable to be particularly devalued (Kitwood 1997). This in turn can lead to interpersonal interactions that undermine personhood and devalue the person, a situation that he labelled malignant social psychology. This term was developed to describe negative caring interactions where, for example, a person is infantilised, outpaced, disempowered, mocked or invalidated.

Malignant social psychology (Kitwood 1997) is created inside relationships within which people are socially positioned, due to a focus on what are considered dysfunctional attributes rather than positioned due to their valued and intact strengths (Sabat 2019). This positioning is created by a malignant narrative whereby normal activities such as walking are labelled as “wandering”, inability to recall events on demand is called “confusion” or expressions of frustration or upset are defined as “aggressive outbursts” or “behaviours that challenge”. Within hospitals, this is due in large part to the biomedical approach to dementia whereby the focus is on the prevention, management, alleviation or eradication of symptoms, rather than trying to understand the subjective experience or meaning of these experiences (Mental Health Foundation 2016). Once this biomedical focus is established there follows the creation of storylines about those diagnosed that emphasise dysfunction even where it might not exist (Sabat 2019). As one expert witness from the Mental Health Foundation (2016) put it “the phenomena of other people labelling...what they see a person saying or behaving, and labelling it with these sorts of neuropsychiatric labels” which are perceived as individually problematic, rather than problems with relationships, communication and understanding.

To counteract this malignant positioning, Kitwood (1997) advocated for a person-centred approach to care where positive and supportive relationships are made and people are facilitated to experience a better quality of life. He believed that this would in turn lead to a situation whereby a person’s resources were no longer dwindling because they were not being treated

malignantly. He recognised that when a person-centred approach to care was used over an extended period people developed a sense of well-being and personal security. However whilst recognising that caregiving can be a truly cooperative and reciprocal engagement that is reliant on relationship building, and by implication communication, the person with dementia was still positioned within the discourse as a passive recipient of care who is reliant on others to be treated well.

Person-centred care rapidly became a significant influencing factor on nursing policy and practice within the UK (McCormack 2004). Indeed it was enshrined into NHS policy in the National Service Framework (DH 2001) as standard 2: Person Centred Care. This standard aimed to ensure that older people are treated as individuals, although details of how this is achieved are missing; and that they receive appropriate and timely packages of care which meet their needs as individuals. Thus placing the person firmly in the position of a care recipient. The thrust of the person centred approach as envisioned by Kitwood is on professional support to facilitate positive relationships (Bartlett and O'Connor 2010) but in acute clinical environments it is generally understood as a professional providing effective and timely care and treatment; rather than on the relational aspect of the model.

Not knowing the person well was recognised in the National Dementia Strategy (DH 2009) as a risk to providing person centred care. This has been additionally verified by the Alzheimer's Society (2016) who found that neither people with dementia nor their relatives felt that staff understood their specific needs or that they were treated with dignity and understanding. The National Dementia Strategy recognised that the negative effects of an admission were not widely appreciated by clinicians, managers or commissioners and that there were marked deficits in the knowledge and skills of general hospital staff. Additionally, insufficient information was sought from relatives and carers leading to under recognition of delirium and dementia. Where hospital care is good people are supported to make choices about their daily routines and care (Care Quality Commission 2014) and are involved in decisions around treatment. However, in general, the medical support available to people with dementia remains inadequate and inaccessible (All Party Parliamentary Group [APPG] 2019).

Personhood as a 'status bestowed' by caregivers upon another person reclaims the person with dementia as someone who matters, but it does not necessarily suggest agency (Bartlett and O'Connor 2010). Thus person-centred care is positioned as a process that may or may not be initiated by staff and within which there lies a relational power imbalance (Bartlett and O'Connor 2010).

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In hospitals this relational imbalance in person centred care places the nurse as the subject acting upon the passive agent of the patient (Prato et al 2018). This jars with the growing national and international narrative of dementia advocates who speak of and for themselves in a growing movement that demands rights and equality; and which has seen the formation of such groups as Dementia Alliance International, the Scottish Dementia Working Group and the UK Network of Dementia Voices – DEEP.

Debates around models of care in acute hospitals focus on the provision of person centred care and whether or not it is being provided (DH 2001; Clissett et al 2013). However, there is still no single agreed definition of the concept partly because person-centred care is still an emerging and evolving area, but also because to be truly person centred, then what it looks like will depend on the needs, circumstances and preferences of the individual receiving care (The Health Foundation 2016). Understanding the patient's narrative is central to providing person centred care and this includes understanding that all narratives are not in words. Even when staff understand that behaviour such as attempting to stand up and move, hitting, shouting or resisting care tasks are forms of communication, staff ability to respond to unmet needs is limited by work demands, fatigue and difficulty in resolving the issues (Handley et al 2017).

Although nursing staff in hospitals recognise that person centred care involves "getting to know" the patient there is also recognition that individualistic care does not always occur, leading to care and communication that can be polite and kind but functional and task orientated, with no opportunity for genuine connection (Cowdell 2010; Prato et al 2018). Cowdell (2010) reported that almost all communication was related purely to physical care and that many interactions were not polite and kind but demonstrated elements of malignant social psychology such as infantilisation (Kitwood 1997), despite the healthcare professional's belief that they were being kind. It is apparent that understanding of the person's narrative is central to person centred care, yet is a skill set that is often lacking, and where present is difficult to implement due to the working environment.

It is generally believed that person centred care should see the people using health services as equal partners in planning, developing and monitoring care. This means putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome (Health Innovation Network 2019). It requires a radical change from the time dependent and task orientated care that is currently provided by acute hospitals (Tadd et al 2011; Dewing and Dijk 2016). The rushed and task orientated care processes do not pass unnoticed by people with cognitive problems who can be aware of, and annoyed by, the lack of meaningful interaction with ward-based staff (Cowdell 2010; Prato et al 2018). Relationships need

to be built through mutual narratives that then enable the person to be at the centre of their own care and treatment.

Dementia advocates believe that person centred care has not generally been translated into practice, and instead has mostly been a tick-box exercise for many organisations (Swaffer 2019). Perhaps they are right. Implementing person centred care relies on the ability to communicate honestly and openly with patients and their families, putting their preferences first and having the time to do so, and building relationships between all the people involved. Person centred assessments and reviews need to have independence, promotion of independence, and recognition of the rights of the person as their starting points. Additionally, implementation of person centred approach to care should not be considered as a one off event; rather it requires a sustained commitment from hospitals to the ongoing facilitation of developments, a commitment both in clinical teams and across the organisation (McCormack et al 2011).

Personhood, person centred care and personal narratives are closely linked. It is important to recognise that people who tell their stories in a way that does not fit the treat and cure narrative of healthcare can have their personhood denied. This is in part due to the way that we currently conceptualise what constitutes narrative (Baldwin 2008) and recognition that if a narrative is not understood a relationship cannot be formed. A person has to be recognised in their attempts to interact and find a place within the people around them; if this mutual cooperation does not occur then the person is negated. It seems extraordinary that whereas healthcare staff will make time to interpret the communication of needs of a pre verbal infant, we are not prepared (trained) to go to the same efforts for a person with dementia. We stick to our biomedical narrative and effectively drown out the voice of a person with dementia.

It is the behaviour and attitude of frontline staff that has the biggest influence on whether a person's experience of care is good or bad (Oliver 2012) and whether relationships can be made and person centred care delivered. Frontline staff are therefore tasked with its implementation but at higher institutional levels policies and decisions are made as to what priorities are set and what risks are monitored that have a direct impact on the delivery of care. Spending time with patients and getting to know them is deprioritised by senior staff and hospital management who instead focus on the provision of task orientated and time dependent care (Bail and Grealish 2016). Care that is organised around the completion of tasks makes it difficult for staff on the ward to prioritise aspects of relational care (Turner et al 2017). Addressing this issue requires intervention at a higher level than the ward, to ensure that senior clinical staff and managers understand that knowing patients as individuals is an intrinsic part of person-centred care, and this takes time and skill.

This higher level organisation needs to support staff to provide good care for people living with dementia, and this requires that hospitals recognise the impact this has on staff workload and roles, and the changes that are necessary to ensure care provision can be adaptive to the needs of the person (Handley et al 2017). Until this change occurs at the organisational level, research will continue to demonstrate a low level and inconsistency of person-centred care, leading some to question if person-centred care is indeed possible (Dewing and Dijk 2016). Perhaps it is also time to ask if this model, where people in reality have been positioned as passive recipients of care processes, is appropriate for people who have dementia, many of whom are now standing up and advocating for themselves.

### **2.6 Social citizenship and Rights**

Using a social citizenship framework Bartlett and O'Connor (2010) have moved beyond the model of person centred care, which places the person as a passive recipient of another person's care, towards a conceptual framework that is founded on the assumption that people should be considered as active social agents in the broader contexts of their lives.

Bartlett and O'Connor (2010) argue for a rebalancing of power by moving away from a uni-directional bestowing of care upon a person with dementia, towards more dynamic and interactive relationships. This recognises that people with dementia not only are influenced by interpersonal and social relationships, but that they also influence these dynamics because they have agency. However, having dementia does not mean that people are reduced to only having relationships that are part of a carer/cared for dyad. Relationships are also present within the wider socio-political contexts within which we all live.

This socio-political context includes how physical spaces are accessed; whether someone is able to access activities and employment or take part in political and campaigning actions. Thus Bartlett and O'Connor (2010) argue that social citizenship is a broadening of the societal context of dementia which recognises that people have the right to be citizens, and that people can be either active or passive citizens depending on their abilities. Active citizens are able to participate in decisions that affect not only their everyday life, but also the lives of people around them; passive citizens get what they are entitled to or have a right to expect as equal citizens. Importantly, "even if someone is unable to participate as a citizen in a conventionally active or political way, they are still seen and treated as citizens" (Bartlett and O'Connor 2010 p35). They describe this relationship of the person to society as social citizenship. Within the context of acute hospitals, people with dementia, as citizens, have the right not to be harmed by the processes of admission; and also the right, if they so wish, to take part in research.

Social citizenship is the “entitlement to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible” (Bartlett and O’Connor 2010 p37). Furthermore, it involves rights, justice, the upholding of social positions and responsibility. Social citizenship repositions the person with dementia as an active agent who is not only entitled to an equitable stake in both private and public life but is prepared to go out there and grab it for themselves.

Bartlett and O’Connor (2010) also consider how research practices can incorporate a social citizenship lens through meaningful participation and freedom from discrimination. They propose the “EXPECT” framework (p95) within which people with dementia can, and should, be actively involved with the generation and translation of new knowledge. Their proposal is that we should reconsider what we regard as evidence, what we research, where we research and how we use the results of research. With direct relevance to this study, Bartlett and O’Connor advocate for the privileging of people’s stories; an extension of the purpose of research to areas beyond the provision of health and social care; the use of participatory and creative research methods that allow inclusion; a re-examination of the ethical issues underpinning research with people who have dementia; using a critical lens that considers power dynamics; and finally translating research into practice in a meaningful way. The EXPECT framework is utilised in this study as the heuristic lens through which the findings are considered.

Social citizenship has started to become reality due to people with dementia demanding that they are no longer excluded from the debate (Swaffer 2014; Mitchell 2018, 2019). Hard work and consistent campaigning has now led to society at large sitting up and taking notice of what people have to say. Wendy Mitchell’s (2018) book has been on the Sunday Times Bestseller list and a BBC Radio 4 book of the week. In it she clearly articulates that although she has dementia, this is only a part of who she is. She is also a mother, a friend and a passionate advocate. She relates an experience at a conference when the previous speaker spoke of the challenging behaviour of people with dementia. She quickly rewrote a section of her speech to include “the challenging behaviour of healthcare professionals, whose ignorant responses distresses us”. She did it for “the many people with dementia who can’t communicate this. Because people don’t get it”.

People are using creative ways to speak about their lives with dementia that move far beyond just interviews. Christopher and Veronica Devas have worked with the artist Greyson Perry on his modern family project. They are depicted on a vase embracing, clearly holding on to themselves and to their relationship; on the other side is a monster that is cutting up Christopher’s memory-physically showing this by shredding his photographs and collaging them onto the vase. The vase is now on display in a national museum and has been the subject of a Channel 4 documentary.

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Despite this activism, there is increasing recognition that people who have a dementia diagnosis are still being treated differently and are not having their rights upheld (APPG 2019). Using evidence that captured the views and experiences of people living with dementia, the APPG (2019) reported that people are treated differently to those with other health conditions, and although respondents saw dementia as a disability, their legal rights were not being upheld. If dementia is universally recognised as a disability then the rights to equality, non-discrimination, participation and inclusion are protected by disability legislation; and it becomes possible to recognise and address societal barriers, including those present within hospitals, that prevent people with the condition living the fullest life possible. Disability legislation can then be used by people to demand their legal rights whilst they are in an acute hospital. No longer will personhood be “bestowed” it will be demanded as a basic right as outlined by the Convention on the Rights of Persons with Disabilities ([CRPD] United Nations 2006).

The purpose of this Convention is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”. The principles of the CRPD include respect for dignity, individual autonomy including the freedom to make one’s own choices, and independence; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity and accessibility.

In direct contravention to the CRPD, people with dementia are further impaired when admitted to an acute hospital due to the social arrangements, behaviours, norms and practices that are in place around them. Complex and noisy physical environments; cognitive outpacing due to biomedical assessment techniques; lack of understanding of other forms of communication that might include embodied language; negative labelling such as confused, wandering and aggressive all contribute to disabling a person once they become an inpatient. As discussed above, the negative consequences of this are well documented.

In acknowledgement of the fact that people with dementia should no longer have to wait until hospitals are able or willing to implement person centred care, there is now a growing movement that is claiming the right to be treated in a way that does not cause cognitive and physical disability. As The UK Network of Dementia Voices - DEEP put it: “A right gives you authority to speak for yourself and to join with others whose rights are not respected or abused”. A rights based approach puts the power back into the hands of people with dementia.

This study includes people with dementia as active participants in the research process, to explore their narratives whilst they are inpatients on an acute hospital ward. Social citizenship is integral

to this endeavour as it encourages narratives to be opened up to critical interrogation as a starting point towards a more socio-political approach to dementia (Bartlett and O'Connor 2010). By interrogating storylines health workers can begin to examine the ways that they contribute to the power imbalances and positioning that have left people with dementia in hospitals where they are in receipt of sub optimal care.

## **2.7 Where are the voices of people with dementia in acute care?**

There is remarkably little evidence within current research that has actively explored the process of being in an acute hospital from the perspective of people with dementia. To my knowledge no study has explored the narratives that are shared by people with dementia when they are inpatients on an acute hospital ward. Research that has considered the narratives of people who have dementia are mainly from those set in familiar settings such as homes, care homes or long stay wards (Kindell et al 2017).

In an integrative review of 104 studies exploring outcomes of hospitalisation, there were no studies that discussed experiences of older people with any kind of cognitive impairment (Fogg et al 2018). Current understandings of what constitutes good or poor care for people with dementia is therefore based mainly on research around the experiences of staff, relatives and proxies.

This exclusion from research appears to be due to a reliance on the use of structured, semi structured interviews and focus groups to explore the experiences of older people in general, and from which people with dementia are excluded for several reasons. These reasons include not being able to understand written and verbal information (Andersson et al 2011); not able to participate in an interview due to recall or cognition (Ekdahl et al 2010; Bridges and Tziggilli 2011; Tadd et al 2011; Funk et al 2018); interviews occurring after the event and relying on accurate recall (Porock et al 2015) or the reliance on information from representatives (Goldberg et al 2012). Even guidance from the RCN such as "Improving Quality of Care for People with Dementia in General Hospitals" (2010) is based on references that include no first hand patient perspectives.

Where people with dementia have been included in studies in acute hospitals, observation has often been the method of choice. One such method is Dementia Care Mapping (DCM) which was developed by Kitwood (1997) as a method for evaluating the quality of care in formal settings. DCM makes "a serious attempt to take the standpoint of the person with dementia and using a combination of empathy and observation" (p4) that requires specialist training prior to its use.

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However, DCM places the person with dementia in the passive position of a care recipient and does not consider the power differentials inherent within these caring relationships (Bartlett and O'Connor 2010). Observational techniques such as this, can provide us with some insight into the journey of individuals in context throughout the day (Baldwin 2005) but they are not able to access the narrative of the person at that moment.

Goldberg and Harwood (2013) in a methodological discussion paper, recognised that patients with dementia are unlikely to describe their own experience, and family carers may not be able to describe the patients' full experience, necessitating the use of multiple methods. They recommend the use of nonparticipant observational tools.

Prato et al (2018) utilised non participant observations of six patients with cognitive impairments that included observations of informal conversations. Patients were not able to comment directly on their hospital stay as they were unaware that they were in hospital, but they were able to comment on their emotional experience of the immediate context, such as their boredom with their surroundings, and their immediate responses to interactions with staff members. Emotional experience was paramount to the patient perspective, and current emotional experience was often represented by discussing past experiences, such as unpleasant conversations with head teachers. Ward routines and staff behaviours were also interpreted through reference to previous life experiences. Additionally, patients expressed annoyance in the lack of meaningful interaction with healthcare workers.

Despite that the context of the acute hospital environment is important, interviews with people with dementia have taken place post discharge and therefore have relied almost exclusively on reports from relatives (Gladman et al 2012, Petry et al 2019). These studies therefore do not reflect the lived experience of the person with dementia whilst they are an inpatient.

Cowdell (2010) used a social participant as observer method, within which there were opportunistic conversations that were initiated by the patients. During these conversations patients commented on feeling not particularly happy, or not well. Non participant observations were used by Featherstone et al (2018) to understand how people with dementia use body movements to resist care, but they did not explore how this was experienced by the patient.

Gladman et al (2012) and Porock et al (2015) used non participant observations whereby the observer attempted to view the world from the perspective of the people with dementia using empathy supplemented with interviews with staff, relatives and co-patients. They found that the disruption from what normally happens caused people to have behaviours and responses that indicated difficulties and distress.

Ferguson et al (2016) in an unpublished thesis, interviewed three patients with early dementia on an acute ward, finding people who were stigmatised, ignored and uninformed. Digby and Bloomer (2016) recruited seven people with mild dementia in a subacute facility and interviewed them in their quiet bedrooms using a conversational approach to explore their feelings about the ward environment.

On a long term hospital ward Nowell et al (2013) explored how personhood was experienced by people with dementia through semi structured interviews, however the interviewees were verbally fluent and able to understand verbal information and sign a consent form. Participants described adjusting both their expectations and feelings about the system to fit the system, rather than the reverse being true, and the approach to personhood they experienced in the ward system was generic.

Recognising that communication between people with dementia and healthcare staff is fundamental to the provision of good quality care, Harwood et al (2018) used videos of interactions to develop a staff training intervention. Findings included the observations that verbal and non-verbal communication of the professional needed to match in order to avoid misunderstandings, and enable the person with dementia to understand the task and participate in them. From analysis of the interactions and conversation, an actor-simulated communication training programme was developed that included attention to both the body language of the patient and the professional. This novel way of developing a training resource is the start of a recognition that communication is skilful, needs training and is fundamental to all interactions.

What all these explorations have in common is the positioning of the person with dementia as a recipient of care processes, and where their words have been considered it is in order to understand the carer/cared for dyad, and not to understand who the person is in that moment of time. By exploring narratives, this study moves beyond considering the person with dementia as a patient requiring care, to consider the personhood that is portrayed and maintained by the individuals.

## **2.8 Summary**

It is widely accepted by both the research evidence and national policies and audits (RCP 2017) that care for people with dementia in acute hospitals is not good enough, and in many cases is harmful. However, what appears to be less well recognised is the absence of the voices of people living with dementia within these explorations.

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Social citizenship and rights based approaches are starting to advocate for the person with dementia to be an active agent, rather than a passive recipient of care. People are beginning to speak out, but not within acute hospitals.

When people with dementia are in hospital, in medical and social crisis, they do have stories to tell. What is clear, though, is that we as healthcare professionals are not equipped to listen. The research that has been considered above, and that does include the perspectives of people with dementia, is reliant on verbal communication or behavioural observations. This study aims to explore both verbal and embodied narratives by using methodology that has not yet been used in the environment of an acute medical ward.

Framing the acute care story as a narrative also brings to attention the fact that this story has been written by those within healthcare and as such can be re-written - if other narratives are acknowledged.

The following chapter explores mobility and immobility in the context of acute hospitals, and goes on to consider how mobility can also be reconsidered as communication.

## Chapter 3 Mobility as a contextual framework

### 3.1 Introduction

This chapter is based on a review of the literature on mobility and independence for people with dementia in acute hospitals (Appendix A). It has also formed the basis for a published book chapter<sup>2</sup>. The following chapter sheds light on the dichotomous relations between mobility and immobility within acute hospitals. I highlight that there is a dichotomy between mobile medical staff and immobile inpatients who have dementia. Potential causes of this asymmetrical relationship are explored, including a culture of restraint that misinterprets a person's body language, and the role of infrastructures and technologies of containment. The latter leads to a consideration of the culture involved in enabling or, in this case, disabling patient mobility.

### 3.2 The meaning of mobility

Mobility bears a number of meanings. In the modern world mobility can be considered as progress, as freedom, as opportunity; but equally mobility can be seen as shiftless, a deviance and as a resistance (Cresswell 2006). A dichotomy that can illuminate the ambivalent interpretation of mobility within a hospital. The hypermobile healthcare professional demonstrates progress in medical practices; and freedom and opportunities to move at will. They are expected to be mobile, movement is a sign of work.

The person with dementia when attempting to move around, leave their bed space or the ward is viewed as deviant. Mobility of this group is something to be prevented lest they fall over and adversely affect safety statistics; or use their movements as an act of resistance to care processes. There exists an institutional containment of wanderings of older dementia patients, whereas conversely there is social affirmation for youthful wanderlust (Holdsworth 2013). Youth is afforded the privilege of wandering (Holdsworth 2013), old age is not.

Mobility, when reconsidered, is not just about getting from A to B but is a way of being in the world; "movement is rarely just movement; it carries with it the burden of meaning" (Cresswell 2006 p3). In a mobile society, immobility becomes a form of disempowerment for an already stigmatised group of people.

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<sup>2</sup> Collins P. (In press) Stories of (Im)mobility: People Affected by Dementia on an Acute Medical Unit. In: Vindrola-Padros, C., Vindrola-Padros, B., Lee-Crossett, K., (eds.). *Immobility and Medicine - Exploring Stillness, Waiting and the In-Between*. Palgrave Macmillan.

However, what is under considered is that mobility is also a form of communication. Featherstone et al (2018) describe a wide range of movements that they observed and interpreted as resisting care, such as attempting to get out (and getting out) of bed, standing and walking around, pulling at the bed rail, approaching the nursing station; biting, pushing, pulling, spitting at, or holding on to staff; pulling or removing IV lines, gastric tubes, dressings, catheters; pulling sheets off the bed or removing clothing. However, they noticed that these movements were always identified and interpreted by staff as a feature of the person's dementia diagnosis that signified their lack of capacity, and as such was to be overcome or managed. They were not recognised as communication strategies.

Reconceptualisation of movements and mobility as a form of communication becomes a way of acknowledging a person's narrative when it is not told verbally, or where language is fragmented. People with dementia have a double stigma constructed for them by society: that of declining cognition in a society where cognitive ability is highly prized; and age in a society that applauds youth and youthfulness. There is an additional stigma for an older with dementia in hospital: that of being immobile in a hypermobile world. Recognition of a person's narrative is an important step in addressing these stigmas.

These varied conceptualised meanings of mobility are utilised throughout this thesis as the contextual framework within which the narratives of the person with dementia are considered. Mobility is considered not only as a way of moving in the world, but as conveying meaning, as a way of communicating and as a part of meaning making.

### **3.3 The mobility/immobility dichotomy**

Whereas mobility defines the hospital it is immobility of the person that shapes the processes of the medical care they receive. The person is rendered a passive, immobile recipient of care provided by a moving, connected professional working in a hospital that relies on the movement of patients through and out of the physical building. The person arrives at the door of the hospital emergency department, their clothing is replaced by a hospital gown; they are placed upon a trolley and become a patient. The sides of the trolley are raised. The patient is moved on the trolley to different departments for investigations. The patient is wheeled on their trolley along corridors to the acute medical unit, slid onto a bed and the bed sides are raised; later the bed is wheeled to a ward, and often another and another ward. Within wards beds are shifted around as the hospital dictates, the patient on their bed moves again. Professional staff move around the beds delivering care that is task orientated and time dependent (Featherstone et al 2018).

It is not the mobility of the person that is important, but mobility in the world that surrounds them. The dichotomy of the hyper mobility of the hospital with the immobility of the patient with dementia produces an imbalance of power and status. The act of moving through the doors of a hospital changes one person into an immobile patient dependent for their care on the healthcare staff around them. Another person crosses the threshold of the hospital and becomes an empowered highly mobile professional. This person is not paid to stand still; movement is a sign of power.

### **3.4 Immobility**

Having a diagnosis of dementia is independently associated with functional decline whilst an acute hospital inpatient (Hartley et al 2017). Additionally, people with dementia have an increased likelihood of acute hospitalisation (Phelan et al 2012) thus increasing their risk of experiencing declines in function.

Low levels of physical activity in hospital are associated with a decline in independence at discharge (Brown et al 2004; Zisberg et al 2011) with half of people aged over 85 admitted to an acute hospital declining in independence (Covinsky et al 2003). It is well established that low mobility levels are common for older people in hospital (Zisberg and Syn-Hershko 2016) with an average of twenty hours each day spent lying down (Brown et al 2009) and a median daily step count of only 600 (Lim et al 2018). Significantly, the effects of low in hospital mobility levels last beyond discharge leaving people with worse independence one month later (Zisberg et al 2011). When older people are active in hospitals it tends to be either with therapy or when undertaking personal care (Lim et al 2018); even at times when opportunities are available for a person to move around such as during visiting times. Older patients remain inactive as the dominant hospital culture is for visitors to sit around the bedside (Lim et al 2018), and for mobility to be associated with task orientated care. Relatives become disempowered by this culture of “care by the bedside”; and instead of the patient being taken to the coffee shop, the coffee is brought to the patient (Prato et al 2018).

Limiting opportunities to be mobile has a significant impact for older people. Many older people are at, or near their functional threshold for dependence (Warburton et al 2006) meaning that any decrease in their physical strength that could be caused by immobility puts them at risk of being unable to carry out functional activities. This was explored within hospitals by Brown et al (2004), who demonstrated a consistently high and statistically significant relationship between low mobility and poor outcomes at discharge. These poor outcomes included functional decline and decreased independence. Additionally, for a person with dementia the ability to participate in

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personal care tasks such as washing, dressing and getting to and from the toilet are important for skill preservation as well as for the maintenance of physical strength. However, on hospital wards nurses take over tasks, such as washing, that patients were capable of doing themselves, thus making patients passive recipients of care rather than active participants (Cowdell 2010).

Mobility is not only fundamental in maintaining independence in functional tasks but is also known to help in decreasing the risk of deep vein thrombosis, pneumonia, delirium and urinary tract infections and help with pain control (Kalisch et al 2013). Beyond these biomedical considerations of mobility are the psychosocial effects of being enabled to move around. The ability to move around is necessary for dignity, engaging in social contact, building relationships, developing confidence, engaging with the world around and maintaining a sense of self.

The low mobility levels and functional decline that are particularly evident with older inpatients who have dementia (Pedone et al 2005), are due in part to the fact that nurses find people with dementia challenging to care for (Alzheimer's Society 2009). Areas of particular concern to nurses can include the perceived risk of falling for such patients when walking around or mobilising, and not having enough time to spend with patients. The longer a person with dementia is in hospital the worse the effect on the symptoms of dementia and their physical health (Alzheimer's Society 2009). This cognitive and physical decline leads to an increase in dependency at discharge which can lead to a person being discharged to a care home rather than their own home (DH 2009).

A further explanation of the low levels of mobility that is experienced by older inpatients who have dementia is that within acute hospitals restraint and restriction are used due to a culture of risk avoidance (Featherstone et al 2018). The organisational and interactional levels of care delivery that focuses on the risk of physical harm has significant consequences for people with dementia. Patients that do attempt to walk around are asked to "sit down, I'll come back to you" and "where are you going? Where do you want to go? This is not a good idea – you're not really safe" (Porock et al 2015 p44). This happens despite research evidence that shows that a removal of restraining actions does not increase the rate of falls but does decrease length of stay, particularly for patients who have cognitive problems (Kwok et al 2012). When a risk management framework is used that focuses only on reducing risks that are important for staff and the organisation, the needs of the patient with dementia can become overlooked and the focus of their care shifts from holistic person centred and enabling care towards surveillance, monitoring (Moyle et al 2010), and often restraint (Featherstone et al 2018).

People who have dementia can resist the care that is delivered to them by refusing the everyday necessities of a hospital admission such as food, hydration, medication and personal care (Featherstone et al 2018). This resistance can manifest in different ways such as physical

resistance, verbal resistance or refusal to comply with the timetabled rounds of the ward. Physical resistance can include pushing away trays or equipment, turning away from staff or attempting to stand, walk, or leave the ward. Attempts to get up from a chair or out of bed are considered risky and are met with restraint from the care staff by either repeated requests to sit down, raised bed rails, sedation, tightly tucked in sheets, low chairs or tables in front of chairs (Featherstone et al 2018). Thus a person's mobility is restricted.

Rather than being interpreted as a form of communication of unmet needs, or something to be encouraged to avoid iatrogenic disability, and enable social connections to be made; moving around for a person with dementia is often labelled as "wandering" or "at risk of absconding" (personal observations). This negative interpretation of physical activity leads to moving around being understood as a purposeless and negative behaviour (Algase et al 2007; Dewing 2011). Additionally, due to the foregrounding by healthcare staff of the risk of falling over, something to be prevented. As a result, rendering people immobile and contained becomes the default way of ensuring a person's safety.

Viewing the mobility of a person with dementia only from the position of risk, prevents the understanding of mobility as a form of communication. Agitation, for example, which can be manifested as repeatedly attempting to walk or move around, is often due to distress caused by pain, thirst or over stimulation in a busy ward environment (Elliot and Adams 2011). By recognising patients' needs and addressing them, the inappropriate use of sedation can be reduced. However, this approach requires staff who are able to interpret this different form of communication, and who have the time to do so.

Further immobility is created by the spatial design of hospitals which minimise the need for movement of the patient. A patient is cared for in or beside their bed; their belongings are in a bedside locker and often unreachable; meals are delivered to the bedside; and for people with dementia who need assistance to move and walk, they are often given a bed pan or commode beside their beds rather than taken to a toilet (Tadd et al 2011; Featherstone et al 2018). Spatial arrangements exist to negate movement (Cresswell 2006) of the patient and minimise time that is spent on caring tasks. The patients with dementia are expected to remain in their place (in or beside their beds) and mobility is portrayed as a threat or dysfunction (Cresswell 2006).

It is understandable that hospitals prioritise the need to reduce the risk of falling. However, focusing on this risk in isolation and not considering the wider implications of risk reduction strategies on people with dementia is problematic. There are unexpected consequences. Using strategies to reduce the risk of falling has led to nurses restricting patient movements and preventing them from walking around (King et al 2018) even though it is recognised that this can

cause poor outcomes for patients. Moreover, guidelines that are used to prevent falls in many hospitals (American Geriatrics Society 2011; National Institute for Clinical Excellence 2013) state that for older people with cognitive impairments there is insufficient evidence to support any recommendations that are currently utilised to prevent falling in hospital. Yet despite this the use of restrictive strategies such as bed sides, minimising functional mobility, excessive monitoring, verbal restraint and chemical restraints are commonly used on acute hospital wards (Cowdell 2010; Dewing and Dijk 2016; Featherstone et al 2018).

Training in moving and handling is a requirement for all NHS staff but this does not include training into how to engage a person with dementia in a task when they have communication difficulties such as slower processing, decreased verbal understanding or sensory problems such as deafness and sight impairments (Kneafsey et al 2014; personal observation). With a lack of training, health professionals often struggle to assist a person physically, leading people with dementia to resist care (Featherstone et al 2018). Nursing staff then “do to” the person rather than enabling them to achieve a task with less assistance (Cowdell 2010; Tadd et al 2011; Clissett et al 2013). There is an under recognition that so called “basic care tasks” take skill and training to achieve in an enabling fashion when staff are working with complex people in a complex environment.

### **3.5 Mobility**

The systems of the hospital permit predictable and relatively risk free movements (Urry 2007) of the patients by rendering the patient immobile and passive; and engendering the professional with the hypermobility necessary to deliver a range of tasks in a minimum length of time to a static patient. The patient becomes reconfigured as “bits of scattered information distributed across various ‘systems’” (Urry 2007 p17) whereby different professionals perform “body work” (Cohen 2011; Twigg et al 2011) on different aspects of the patient. The doctor delivers a diagnosis; the nurse delivers the medication; the care assistant delivers personal care; the physiotherapist delivers mobility. No one person attends to the entirety of the patient. This treatment of the patient’s body as a material object like any other, physical, malleable and ultimately divisible, ignores the fact that bodies are unitary, communicative and mindful (Cohen 2011). The patient waits, immobile and disempowered for people to come to them.

The fracturing of professional interactions into multiple parts undermines efforts to treat the patient holistically, build relationships or provide continuity of care (Cohen 2011). For a person with dementia the ability to move around and to function as independently as possible is crucially reliant upon social connections as well as environmental conditions (Marshall 1997). They need

people who have time to communicate, and time to help in a way that is familiar to them. Hospital culture is about efficiency, movement, speed. It is task orientated and time dependent. Making connections and relationships becomes all but impossible in a hypermobile environment.

There is a human cost to this hospital hypermobility; the mobile professional has not enough time to care for the patient, and a division of labour is introduced with parts of the “body work” assigned to lower skilled workers (Cohen 2011). The time and skills required to provide care for an older person with dementia are not available. The impact of this imbalance is in plain sight but it remains unaddressed.

The immobility of the patient with dementia contrasts with the hypermobility of the hospital around them. Hospitals rely on “patient flow” - the movement of a patient through the physical space of the hospital from the emergency department to the wards and back into the community, thus freeing beds for arriving patients. The consequences of poor patient flow include patients being admitted as ‘outliers’ to wards that are not suited to managing their care, which may mean they have worse clinical outcomes; and inpatients are moved between wards to make room for newcomers (Tadd et al 2011). This hospital driven movement of the patient can result in poorer outcomes and negative impacts for people with dementia such as increased disorientation and anxiety (Tadd et al 2011), particularly if bed moves occur at night. Despite that night bed moves are known to have significant detrimental impact on people with dementia both staff and carers continue to report that bed moves are a major barrier in providing high quality care for people with dementia (RCP 2019).

The movement of the patient between physical parts of the hospital is not considered as part of the care processes but is considered in terms of hospital operational efficiency; the mobility of one system is inevitably at the expense of the immobility of another (Bissell 2007). At each point in this journey the patient is considered in their place on the ward, sedentary, fixed and immobile. This immobility or “stuckness” (Hage 2009) has been normalised within hospitals and accepted as an inevitable experience of an inpatient stay. Stuckness is by definition a situation where a person suffers from both the absence of choices or alternatives to the situation they are currently in, and an inability to grab such alternatives even if they are present (Hage 2009).

The amount of movement in a hospital means that it is noisy, and noise can be stressful for people with dementia (Marshall 1997). Acute wards are loud with conversations, footsteps, equipment alarms, buzzers, rattling trolleys and floor cleaning machinery. Cognitive testing is regularly performed by doctors or psychiatrists within hospital settings, and yet noise can detrimentally effect the outcome of cognitive tests in older adults (Dupuis et al 2016). Allowing testing to take place in a noisy environment further disables a person and can lead to them being

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considered less cognitively able than they actually are. This in turn can lead to restriction and restraint (Featherstone et al 2018).

Within this noise and hectic movement of the ward the voices of people with dementia are figuratively and often literally silent. The imperative of the busy professional is for a patient to answer questions quickly and to tell a clear, concise linear story enabling a diagnosis of their symptoms and the implementation of a treatment plan. And yet, within the first forty eight hours of an acute hospital admission a person who finds recall on demand difficult, who is in a stressful environment, who may have linguistic and cognitive challenges and may be disorientated to time, place and situation will have had interactions with, and been asked questions by at least twenty four different people who move in and past their bed or trolley space (personal observation). Manifestations of frustration at this ceaseless questioning and noise can be labelled as “aggression”.

Hospital care processes are based on the assumption that patients will be able to express their wishes, answer questions, acknowledge the needs of other patients, comply with treatment and move through the system as required (RCN 2010). Yet this relies on the professional having enough time to stop, listen, understand and in many cases observe. It is also reliant on the person with dementia understanding what is happening, feeling safe and being enabled to participate in their care.

### **3.6 Summary**

This chapter started with developing a broader meaning of the term “mobility” to consider movement to be a form of communication, as well as body movements, or moving around.

The chapter has reviewed the literature that has explored mobility and independence for people with dementia when they become inpatients in an acute hospital ward. Low levels of mobility are apparent, and this is now well recognised as having a detrimental effect on patients.

The chapter has also brought into view the juxta-positioning of the immobile person with dementia with the hypermobility of the hospital around them. It has also suggested that by reconsidering movements as indications of emotional and procedural agency, rather than manifestations of the dementia diagnosis, there is a possibility that patient narratives can be accessed in people who are becoming less verbally fluent. The broad meanings that can be brought to the concept of mobility within the acute hospital context make mobility an ideal lens through which to view patient narratives.

From previous chapters it is clear that the processes of care for people living with dementia in acute hospitals are sub optimal; that people lose independence and are less mobile after admission and that the hypermobility of the hospital environment is difficult to cope with. It is also known that there is limited research that includes the views and first hand accounts of people with dementia whilst they are inpatients.

The following chapter considers the narratives that are shared in acute hospitals, and asks if embodied language can be a way into understanding a person's narrative whilst they are an inpatient.



## Chapter 4 Narratives in acute hospitals

### 4.1 Introduction

Previous chapters have outlined that care for people who have dementia when they are in an acute hospital needs improvement and that people lose mobility and independence whilst an inpatient. It is significant, therefore, that the World Alzheimer's Report (Prince et al 2016) stated that within acute general hospitals "a striking finding from the published literature was the almost complete absence of the voice of the person with dementia, whose experiences, perceptions and views seem not to have been systematically studied" (p 64). Which leads to the question: within acute hospitals whose story is being told?

Dementia communication has rarely been studied in the challenging environment of the acute hospital (Harwood et al 2018). Studies that have considered the narratives of people with dementia, or which have attempted to understand their experiences, have taken place in long term care or at home where people are comfortable, supported, or at least in familiar surroundings (Kindell et al 2017). When a person with dementia is in hospital they are in an unfamiliar environment, unwell and often without familiar faces around them. It is likely that the narratives that are told will be very different.

This study is one of very few that takes place on an acute hospital ward and in addition, all the participants are in either medical or social crisis.

### 4.2 The changing role of narrative in healthcare

Historically the patient's narrative, or story of their illness, was central to the doctor patient relationship, placing doctor and client on nearly equal footing; and providing these early patients with a distinctive framework for understanding episodes of illness (Fissell 1991). The stories themselves were the focus of scrutiny within which both meaning and treatment could be negotiated. With the development of modern hospitals, doctors came to focus on bodily signs and symptoms and the patient's narrative became redundant (Fissell 1991). This emphasis on physical diagnosis privileged the doctors' medical knowledge and placed the patient in a position subservient to this knowledge. In the biomedical narrative of modern day medicine the doctor has taken over the patient's own words and replaced them with medical terminology.

Yet narratives are essential to healthcare, but who is listening and what are they hearing? For those living with dementia the difficulties encountered with expressive language, loss of memory

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for recent events and disorientation to place and time may limit the possibility of engaging narratively with the world and with others (Baldwin 2006) because other people expect a different narrative than the one that is provided. This is especially true in the context of acute healthcare which relies heavily on the biomedical interpretation of a patient's story and the search for the medical "truth" in order to form a bodily diagnosis.

The history of the patient's presenting condition accounts for 80% of the diagnosis (Cooper and Frain 2018) but dementia may cause a person's narrative to be fragmented, inconsistent and incoherent; to be "confused" or "untrue" in the eyes of the medical practitioner. Clinical histories require the story to be time ordered and reflective with accurate recall of symptoms; the conveying of abstract concepts such as how a person is feeling; descriptions of pain; the impact of symptoms and an understanding of what is happening. Within this exchange the professional is assumed to know more about the patient's illness than the patient; and the lived experience of the illness does not automatically count for much in diagnosis and treatment (Charon et al 2017). This is especially relevant for people who are not well and who are not fluently articulate. If time is made for a clinician to unconditionally listen to the patient's story, an understanding of beliefs, values, emotions, hopes, fears, identities and relationships can be gained. However, even the most sensitive clinician, when trying to understand a patient's story has narrative expectations: that the narrative will involve a sequence of events, experiences and values and that these will be organised in such a way that sense can be made out of the events.

Within the hypermobile acute hospital where resources are limited and demand constantly increasing, the aim is for rapid evaluation, intervention and discharge, leaving little time for rapport building, giving comfort and nuanced communication with those with communication challenges (Harwood et al 2018). The person with dementia becomes a patient, the doctor attempts to elicit the required biomedical narrative using set questioning in order to reach a diagnosis. This reductionist and fragmented medicine leaves little time or regard for the singular aspects of a person's life and creates a social injustice that contributes to discriminatory practices (Charon et al 2017) because the less articulate patient is effectively silenced. The person who does not remember is at risk of being discarded as lost, as inhabiting permanent patient hood, rather than being seen as a mother, sister, grandmother or partner who has something important to say (Taylor 2010); the stories that they do tell are discounted as not contributing to the medical diagnosis.

Thus, in the context of evidence-based medicine where the belief is that all truth has become knowable through rigorous science and sophisticated diagnostics, the ambiguity and complexity of patient stories renders them too often at the margins of medical practice (DasGupta 2006). The

person telling their fragmented story is framed as the “untrue” patient who does not fulfil their role as thankful, earnest, obedient, and honest (DasGupta 2006). The temptation within the clinical encounter is to view this erosion of memory as an indicator of the unravelling of self and personhood, as the memory for information is considered as the most important function; there is limited time to consider the importance of memory for sensation, emotions and aspects of relationship (Killick and Allan 2001).

There is a power imbalance in the narratives of the acute hospital. The biomedical model of history taking creates a malignant social psychology, by outpacing the person with dementia (Kitwood 1997) through the sheer volume of unilateral questions. The interaction is in the control of the health professional; as is the length of the interaction, the subject matter, the manner of its closing and the interpretation of its content (Killick and Allan 2001). Even the wording of the clinical encounter “history taking” positions the patient as passive within the interaction. Conversely, what is experienced by the person living with dementia as a radical loss of power, may be felt by health professionals as an oppressive and exhausting form of responsibility (Killick and Allan 2001) because the professional is charged with attending to the needs of a person in a task orientated and time dependent manner which leaves little time for relationship building, understanding and compassion.

Yet increasingly it is recognised that the building of relationships between healthcare professional and patient – relational care – is fundamental to good quality care for older people (Bridges et al 2019). Where relationships are seen to be effective and patients feel involved with their care, experiences of hospitalisation improve (Bridges et al 2019). The building of relationships relies on effective communication but the present task orientated model of acute care that relies on the biomedical narrative does not allow for the nuanced understanding of communication strategies that people with dementia may employ.

Patients living with dementia can use a wide range of communicative skills that vary with time and context, and require real-time awareness, assessment and adaptation by the health-care professional (Harwood et al 2018). However, there are barriers in practice to using more subtle forms of communication, such as awareness of body language and appropriate turn taking, which include limited time to interact with patients, and a lack of a critical mass of consistently trained staff (Harwood et al 2018). To receive the creative speech of another person is to synchronise one’s very existence with theirs: challenging the notion of the clinician as disembodied mind, treating a body dissociated from the personhood of the patients (Charon et al 2017). To receive and understand the narrative of others takes time. However, the reliance on words, and the

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speed within which all relational transactions take place within the hospital act to narratively disable the person living with dementia.

The hypermobility of the hospital ward is a further barrier to narrative expression when a person cannot articulate their story rapidly and articulately. In a busy and noisy acute medical unit, people living with dementia may experience a loss of control and a loss of narrative opportunity because of limited social interaction, causing them to become narratively dispossessed (Baldwin 2006). Space within which narratives can be told is constrained through the mobilisation of the meta-narrative of dementia which defines the person in terms of decline, loss and fragmented cognitive functioning; and the interpretation of expressions of agency such as walking about, becoming angry or upset as symptomatic of the dementia itself (Baldwin 2006).

This narrative dispossession need not happen if we reconceptualise what a narrative is and learn how to listen without prejudice. Words are so forefronted in the clinical story that wordless communication is often bio medicalised and thus misunderstood. It is useful to juxtapose the embodied language of a person diagnosed with dementia and that of a pre-verbal child. A child that is unusually quiet or withdrawn, hitting people, cowering, hiding or running away will be treated with concern, physical touch and an effort to understand what the child is experiencing so that they can be comforted and made to feel safe. An adult with a diagnosis of dementia displaying such behaviours in a clinical environment will be interpreted as showing “behaviour that challenges” or as being deliberately difficult, due to misinterpretation of this form of communication (Handley et al 2017). If we listen to the narrative of a person with dementia with not only our ears, but with our eyes and our compassion as well, a new interpretation and understanding can be reached. Leading perhaps to a decrease in the use of restraint and restrictions such as bed rails and sedatives (Featherstone et al 2018) which are sometimes used when the person’s narrative is not recognised or understood.

What flows from this is that narrativity – and through this a demonstration of personhood, of who we are in that moment in time – is a performative activity that involves much more than just words. Such activity requires agency and opportunity, and the ability to move and interact with others. People with dementia, however, may be denied these: denied agency through the way we currently conceptualise what constitutes narrative and narrativity (Baldwin 2008); and denied opportunity due to the hypermobility of the hospital ward that renders the patient immobile and beside their beds. Where staff do understand that movements and actions are communication strategies, they are more likely to address physical needs such as supporting mobility or offering pain relief, rather than attempting to control and restrict the person (Handley et al 2017).

However, the understanding that these bodily narratives may be expressions of not just functional

needs, but of needs for companionship, compassion and relationships is not yet widely understood.

It is becoming apparent that for a person living with dementia who becomes an inpatient in an acute hospital, a different approach to communication and relationship building is required, and that this needs to acknowledge different forms of narrative expression, and be less reliant on the biomedical model of narrative.

### **4.3 Narrative Colonisation**

The biomedical approach to illness works to colonise the narrative of the patient. The ill person not only agrees to follow the treatment that is prescribed, but to also tell their story in medical terms that are expected by the healthcare professional, and to which the professional will listen (Frank 1995). This narrative colonisation is problematic for people who have conditions, such as dementia, which are not curable and which last throughout the remaining lifespan. Conditions that fundamentally change the way that the person is, and how they relate to the people and the world around them; in other words people who are living within a changing life story (Frank 1995).

Narrative colonisation by medicine is increasingly questioned in a world with a growing number of people living with long term health conditions. The “post-colonial” ill person demands to speak rather than being spoken for, to represent oneself rather than being represented, and reject the reduction of their experiences to a mere set of symptoms (Frank 1995). People want the human, personal aspect of their condition to be understood from their perspective; to be given the space to tell their own story. An acknowledgement that life moves on, stories and experiences change and what was experienced becomes experience in the telling and its reception (Frank 1995).

There are many people living with dementia who are well and articulate who are refusing to be treated as “clinical material” in a medical story. Instead they are claiming and telling their stories via blogs, books, activism and conferences (Swaffer 2014; Mitchel 2018). However, one of the main obstacles for someone living with dementia to having their story heard in a hospital is that as the condition progresses verbal ability starts to decline. And it is in the later stages of dementia that people are most likely to be hospitalised.

We live in a hypercognitive culture whereby cognitive ability is seen by many to determine the value of human life; and where this disproportionate emphasis on cognitive function and the articulate use of words robs our ethical system of a basic equality amongst humans (Post 2000). Post draws attention to the ways in which a hypercognitivist society fails to maintain and enhance

the emotional and sensory domains of experience which are shared by all human beings regardless of their cognitive capacity. To enable a person with moderate or severe dementia to express their emotions and feelings, and more importantly to enable these expressions to be understood, is a challenge in hypermobile acute hospitals. To recognise humanity and build relationships in the frenetic environment of an acute medical unit takes skill to understand another's narrative. Learning, utilising and passing on those skills relies on a supportive environment for both patient and professional. It requires listening to those who live with dementia and acting on their stories.

### **4.4 Narrative based medicine**

Narrative based medicine emerged at the turn of the 21st century to challenge the reductionist, fragmented biomedical approach to medicine that holds little regard for the singular aspects of a patient's life (Charon et al 2017). Narrative based medicine acknowledges that the knowledge of another person's narrative can deepen therapeutic relationships due to the understanding that experiencing and treating sickness are language based events, and that illness changes everything for the patient (Charon and DasGupta 2011). In clinical practice health professionals are trained to take a patient's history that is looking for the "facts" of the illness; anything that cannot be classified as a fact is given no place in the formal medical record. Thus the complex, emotional and contextual meanings of the patient that are found in their personal narratives are not included in understandings of the illness (Greenhalgh and Collard 2003). Narrative based medicine seeks to redress this.

The three foundations of narrative based medicine are attention, representation and affiliation (Charon 2005). Attention is the heightened focus and commitment that a listener can donate to a teller – all tellers of a story require a listener. The listener needs to suspend their self in order to be receptive of the language and experiences of the other.

Representation gives form to what has been heard or perceived thereby making it visible to both listener and teller. This form represents how the listener (the clinician) has heard the story. This can be a private process, or the representation can be shared with the teller (patient) to ensure that the clinician has understood the story in the way that was intended. Finally, affiliation which is the relationship that is formed between the clinician and the patient from deep attentive listening and understanding. It is from a point of affiliation that relationships can be made.

Narrative based medicine is pushing the pendulum back towards the patient, and recognising that the story around and behind the patient is fundamental to an understanding of not just the presenting complaint but the whole person. However, until recently, narrative based medicine

has most often been based on the spoken or written word which is problematic when words become more limited; but there are now attempts to construct narratives in mediums other than words.

A musician in residence at an acute hospital spent time with people with dementia whilst they were inpatients, following them to appointments and diagnostics and turning their story into music. He represented these peoples' narratives as a six movement chamber work:

*The musical situation of the saxophone is symbolic of that of the patient, not always clearly heard, sometimes overwhelmed by the others. But, when given the chance, when listened to, that line becomes stronger and more assertive* (Moss and O'Neill 2019 p2012).

Claffey (Claffey and Coughlan 2016) dancer in residence at the same hospital, worked through dance movements to understand the person's narrative, recognising that often the story is not told in words:

*I had a sense that through touch via each person's skin I was meeting the person's very essence and they me. As we age, our other senses may not be as sharp but our need for touch never diminishes.* (Moss and O'Neill 2019 p2013).

These artists, working within a clinical environment illustrate that artistic knowing is different from conventional clinical paradigms and that there are benefits in bringing the two together. The chamber work illustrated the isolation of the person with dementia and their attempt to assert their voice amongst the cacophony of noise; and the dance piece highlighted how people with dementia respond to touch and through it convey meaning (Moss and O'Neill 2019).

## 4.5 Narrative typologies

This study explores the narratives of people living with dementia via the mediums of video, audio and written representations of what was seen, heard and experienced. During analysis of the narratives that have been collected in this study I began to recognise that the stories fall into certain typologies, and that characterising them was one way in which a deeper, more reflective understanding could be found. The typologies that resonated most with the narratives that I collected were those of Frank (1995).

Frank (1995) suggests that the reason to propose types of illness narratives is to avoid the subsuming of the person by the general illness narratives and to encourage closer attention to the stories that ill people tell; to use the types of stories as listening devices. The story that we expect in healthcare is the one that is able to help with diagnosis and treatment, but often in a hospital, a

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story is told that is not isolated or contextual, and the listener flounders and does not have the skills to listen. Frank's framework of narrative typologies is useful to enable the hearing of stories as their own truth and to help recognise that people telling stories do not only describe their bodies, as in the biomedical model, but that their physical bodies give the stories their particular shape and direction. Stories do not simply describe the self; they are the self's medium of being (Frank 1995).

Frank describes story telling in illness as a way to reclaim and retain self; as a way to repair the narrative wreckage of disease. During an acute medical admission the patient's narrative can become colonised by others and the person is left with a shattered narrative. Nowhere is this more important than in the stories that are told by people who have been diagnosed with dementia. Stories, when heard and understood, can be utilised to define a person's sense of self against the overwhelming medical narrative. Frank contends that the "self is being *formed* [his emphasis] in what is told" (p55). He proposes three types of narrative by which an ill person can achieve this formation of self: restitution, chaos and quest.

### 4.5.1 The restitution narrative

At the heart of most medical encounters, at least at the beginning, is the hope that a cure can be found or that the problem can be fixed. This understanding is at the heart of the biomedical narrative – the body is given over to medicine in the expectation of restoration to health.

Restitution stories are the stories that we hear the most about, and which are celebrated in the media with accounts of new cures for cancer, heart disease, infertility or the common cold (Frank 1995). Restitution narratives allow an ill person to create a story about themselves, "today I am ill but tomorrow I will be better"; it is a narrative that is desired by the story teller, and is also the story that is expected by those around them. Modern culture places health as the normal position towards which all should aspire. A problem arises when the ill person does not find restitution, or when someone who can only tell restitution stories encounters someone whose health will not be restored, such as someone with a diagnosis of dementia.

A restitution narrative can be present, even in the face of an incurable condition. On an acute medical unit, people who have a diagnosis of dementia also have other diagnoses such as pneumonia or heart failure that have caused the acute hospitalisation. The person can be treated for these acute conditions, and will, in some cases recover. However, the underlying condition, the dominant narrative of dementia, will still be there, and in many cases will be worse. These people require different narratives but "medicine's hope of restitution crowds out any other stories" (p83). The narrative that is being told is not heard.

#### 4.5.2 The chaos narrative

According to Frank, chaos narratives are the opposite of restitution wherein the plot imagines life as never getting better. Chaos stories cause anxiety because they represent the triumph of the illness over the treatment; they represent a failing of our healthcare and show how easily it could be us in this story. They are frightening. The anxiety that these stories cause prevents us from listening to them.

The absence of narrative structure where the narrator tells of experiences without sequence or causality causes the stories to become chaotic. The nonlinear structure of these stories makes them hard to hear and their meaning difficult to discern. Significantly for a person who has dementia the story is not heard because of this absence of structure. The person is inside of their narrative chaos; to verbalise their story requires the ability to reflect on their experience and verbalise this to others who are on the outside. But in the lived chaos there is only the immediate moment; the person “is imprisoned in the frustrated needs of the moment” (Frank 1995 p98). Thus, the true chaos narrative cannot be told but can only be lived, the voice is subsumed in interruptions, interrupting itself as it seeks to tell. A narrative that can be ordered and told is not chaotic.

Despite that Frank recognises chaos stories as being the most embodied form of narrative, he still discusses them in terms of their fractured verbal structure and the gaps between the words, rather than in terms of embodiment. The story of chaos cannot be told in words alone from within the chaos; to understand it is to use interpretation, non-judgemental observation and an awareness that there is a narrative, but the listener may not have the tools to understand it. The alternative is to deny the chaos story, to deny the person has a narrative reality and to fail to create understanding and build a meaningful relationship.

#### 4.5.3 The quest narrative

In Frank’s third narrative typology, the quest, illness is envisioned as a journey, although what is quested for may never be completely clear; the quest narrative supposes that something is to be gained by the person from the illness experience. Wendy Mitchell’s story is a classic quest narrative of dementia. Through blogs, public speaking events and working with agencies to change policy and practice, Wendy takes control of the dementia agenda and uses her story to influence others (Mitchell 2018, 2019). Whereas restitution stories are about the triumphs of medicine, and are stories about the self only by default, the quest story gives the person’s perspective and in doing so chaos is held at bay (Frank 1995). The person reclaims their story and claims a position of power against the societal positioning of helplessness.

Quest narratives do not need to be told chronologically, instead present circumstances become occasions for the recollection of past events (Frank 1995). The story can be narrated as fragments that may or may not come together as a complete whole. Frank's quest narrative could also be used to represent how a listener looks for the narrative of a person living with dementia; from the outside looking in, dementia appears to constantly interrupt the narrative of life in the past, whilst the past also interrupts the life lived in the present. The story is there, but it is fragmented and needs to be searched for and reassembled.

### **4.6 Scaffolding, collaboration, entanglement and fragmentation.**

Listeners to a story have expectations of what they are going to hear. There is an expectation of place, characters, a series of events and a denouement. There is an expectation of being able to follow and understand the story. In dementia the person may use a narrative that is out of context, does not follow a plot line, is fragmented or entangled with the stories of the listener (Hydén 2018). At times the person as narrator may move freely through time reliving previous roles such as child, sibling, worker or parent. This changing character of the teller violates narrative norms and makes the story hard to hear and probably hard to tell; the story can become entangled in itself and the listener can equally become entangled by the disorganisation of the plot (Hydén 2018). A narrative is necessarily a shared experience between the listener and the narrator. To produce a narrative, especially an autobiographical one therefore necessitates collaboration between the person living with dementia and the listener (Hydén 2018).

Collaboration requires the conversational partners to work together in order to construct a narrative. As the person living with dementia becomes more compromised in their linguistic skills and more cognitively challenged the conversational partner has to engage actively in collaborative compensation (Hydén 2018). The conversation becomes a joint activity whereby the person with dementia is supported to make their contributions by the listener; however inherent in this support is the risk that the story will become colonised by the conversational partner who could take over the story telling. Compensatory shifts are made in the conversation in order to facilitate participation so that even in the later stages of dementia when a person communicates with bodily actions like gaze and touch these can be reciprocated and understood as communicative resources (Hydén 2018).

The processes of dementia, whilst making it increasingly difficult for a person to tell their own story, only prevent the story from being told if the listener is not sufficiently resourced to be able to support and collaborate (Hydén 2018). This recognition moves the impairment away from being an individual property, and makes it a property of the interacting participants; and a

practical problem that can be resolved if conversational strategies such as scaffolding (Hydén 2018) are used.

The theory of scaffolding was originally proposed by Bruner (1985) when working with children, to explain the process whereby an adult assists a child to achieve a task or solve a problem that they would be unable to manage alone. The child completes the elements of the task that are within their range of competence and the adult supports with the other elements in order to achieve success and enable the child to learn. This model does not exactly fit to interactions with people who have dementia (Hydén 2018) because Bruner's model relies on the roles of teacher and student being fixed in relation to each other and the goal of the scaffolding being that the teacher is teaching. The student is the passive learner and the teacher actively assists. In conversational interactions with people who have dementia both participants may play an active role in constructing meaning by, for example searching for a word or a memory (Hydén 2018). Additionally, the goal of the interaction is not the problem solving in itself but the successful construction of an interaction (Hydén 2018).

Scaffolding takes place within a conversation when the person without dementia makes contributions that facilitate the other person to understand, respond and make contributions of their own (Hydén 2018). Scaffolding works best when conversational partners know each other well or have an understanding of the other's past history. Conversational partners can become co-tellers, with the person with dementia contributing as much as they are able and the partner filling in narrative gaps or inconsistencies (Hydén 2018).

There are three forms of narrative scaffolding that can usefully be employed by people without dementia to support conversation and relationship building (Hydén 2018) for people with dementia. Firstly, there are activity frames which include the environment, wording or topic which when used can increase the ability of a person living with dementia to make conversational contributions. Activity frames, particularly in the form of environment are utilised in hospitals, where a person may be taken somewhere quiet with less distractions to enable them to focus their attention. However, the general activity frame on an AMU is noisy and hypermobile leading to a disabling of narrative, rather than enabling.

Secondly, there are scaffolding actions that will increase the likelihood for constructing joint meaning. These actions can take the form of using open or closed questions depending of the verbal ability of the person. At times, questions can help the person to continue their topic and not lose the thread of the conversation; or by using no questions and using touch or eye contact, gaze and gestures to mirror the others movement responses (Killick and Allan 2001). Thirdly, there is repair activity whereby problems within the narrative, such as historical inaccuracies or

the wrong word, are repaired by either or both participants. However, repair can lead to narrative colonisation whereby the person's story is overtaken by that of the conversational partner.

Hydén and Örvulv (2009) recognised that having dementia makes it difficult to comply with the cultural, social and linguistic conventions that support the telling and interpretation of narratives that have been outlined above. However, they also recognise that verbal narration is not the only way that a person with dementia can tell their story and that there is a performative aspect of autobiographical narratives that has not been explored in dementia research. Thus embodied language where the body and other non-verbal communicative resources are used can become a way of communicating important aspects of the narrative. Hyvärinen et al (2010) recommend that the listener suspends their preconceived narrative norms and treat these different story structures and embodied language as invitations to listen (and watch), also recognising that sensitivity to these stories will require new methodological solutions.

### **4.7 Embodied language**

Connecting with another and providing care that is truly centred on the person relies on the building of relationships (Bridges et al 2019). Relationships are built on mutual understandings, communication and the sharing of narratives about self. Much of the literature explored so far has focused on the role of verbal language, fragmented, entangled or otherwise, of the person living with dementia. However, the body is an important means by which people engage with the world, and express their understanding (Kontos 2005).

Face to face encounters are socially organised and inside of which we manage ourselves in such a way as to maintain our identity (Goffman 1967). Goffman recognised that a status in society "is not a material thing that can be possessed and then displayed; but it is a pattern of appropriate conduct, coherent, embellished and well-articulated" (Goffman 1990 p81); through which we maintain our place in the world. Goffman's contention was that we are not individual actors in our social worlds, we are teams of actors who are dependent on each other in order to establish and maintain our social position. For people who have dementia, the interaction may need scaffolding by others in order to maintain their place in society, have their narrative understood and be able to build relationships (Hydén 2018).

Goffman focuses in on the micro actions and micro movements that accompany words and which we make consciously and unconsciously. Body positions, facial expressions, hand movements or the way that we dress indicate who and what we are to the people with whom we interact. Goffman utilises these observations to theorise that power or powerlessness is communicated at the micro level through people's face to face embodied communication. Recognition of this is

relevant to people who have dementia when a person is not able to articulate their identity through the use of words, as an understanding of a person's language when it is expressed through the body is fundamental to the building of relationships upon which care and compassion are based.

Goffman (1967) recognises that within the walls of a social establishment there are teams of performers who cooperate to present to an audience a given definition of the situation. Inside the walls of an acute hospital the biomedical model of healthcare has narrative and performative expectations from the participants: the all-knowing and powerful professionals and the compliant and coherent patients. What then of those who do not have a role in this enactment? These are the most vulnerable of people who are poorly served by the processes of healthcare that are currently used, because at the most fundamental of levels, that of communication of narrative, they are silenced because their stories do not fit.

Merleau-Ponty (1962) recognised this use of body language in the projection of status and identity and theorised it as the pre-reflective body that does not require a cognitive form of consciousness. Merleau-Ponty argued that this pre-reflective body is in itself intentional and capable of performing actions that are inherent to the body, and distinct and apart from conscious action. He uses as an example the scratching of a mosquito bite which requires no conscious thought to locate the spot and engage the hand to scratch; this is an action that is pre-reflectively performed and is in itself never learned. The body itself holds knowledge of self, and is not just a vessel through which self is presented.

Kontos (2005), working with people with dementia, uses Goffman's and Merleau-Ponty's theorising to argue that the body must be recognised as having an agential role in the constitution and manifestation of selfhood via embodied language. Kontos describes the body as an "active, communicative agent, imbued with its own wisdom, intentionality and purposefulness" (p558) which is separate and distinct from cognitive control - the body is itself a source of selfhood that does not derive its agency from cognition. Even when dementia is severe, these body movements can still demonstrate a practical competence in engaging with the world and expressing selfhood; of telling the world around "who I am". Witness Lena, at the start of this thesis. In this way, the self is fundamentally intersubjective, embodied, and interactional with cognition being spread throughout the entire being (Rosen 2017).

The body can therefore be considered as integral to the conveyancing of information about self, and this becomes increasingly important as verbal fluency declines. However, care practices are still premised on a model of dementia that denies the body an agential role in the manifestation of selfhood (Kontos 2005) and thus personhood. People are not only face to face in conversation

but body to body (Goffman 1967; Hydén 2018). Leaving the physical body out of the understanding of stories is problematic for people who use resources other than words, such as gestures, touch, gaze or bodily movements. Embodied language, where facilitated and understood can become a way of communicating important aspects of the narrative. This necessitates a suspension of the listener's preconceived narrative expectations and instead treating these story structures and embodied language as invitations to listen, touch, watch and connect (Hyvärinen et al 2010).

## 4.8 Summary

This chapter has considered the place of patient's narratives in acute hospitals. It has recognised that the narratives that are shared by people who have dementia can become colonised by the dominant biomedical narrative. This narrative places individual experiences at a low level of importance, below that of coherent patient histories and results of medical examinations and tests.

For people who are not verbally fluent, and who might struggle to tell their story in the expected linear form, the biomedical narrative silences their voices. Yet in places other than hospitals, which are familiar and supportive, people with dementia have been able to take part in conversations and interactions with the assistance of conversational partners.

Additionally, narratives are recognised to be composed of more than just words, but also facial and body movements, touch and eye contact. Language can be embodied and if attended to can contribute to a deeper understanding of the person.

What is missing is the exploration of narratives of people with dementia when they are in an acute hospital. In hospitals, interactions are often multiple and fleeting and the person with dementia is in medical or social need. How does a person relate their story, and relay a sense of self in a hypermobile world where they are placed in or beside their beds, and rendered powerless?

The following chapter describes the methodology that has been used in this study to explore what narratives are told by a person in a hypermobile acute medical unit.

## Chapter 5 Methodology

### 5.1 Overview

This is a narrative enquiry within a constructionist epistemology, whereby experiences and meaning are considered to be socially produced, and a unidirectional relationship between meaning, language and experience is not assumed. I worked on the assumption that people with dementia have narratives to share that are not solely about being a recipient of care in an acute hospital. My ambition was to bring to the foreground these narratives and to understand them through a lens of mobility. This chapter explains the methodological rationale behind this narrative enquiry, and the methods employed to gather data.

There are limited qualitative explorations involving people with dementia in acute hospitals, and these have tended to either involve interviews (Cowdell 2010; Bartlett 2012; Clarke and Bailey 2016; Digby et al 2017) or observational studies (Featherstone et al 2018). Sabat (2001) argues that the use of interviews necessitates asking point blank questions that are unilaterally chosen by the researcher and require recall of events; this can cause anxiety and distress to someone with dementia, and an associated feeling of failure when questions cannot be answered. Additionally, where interviews have been utilised they have generally taken place once the person has left hospital (Porock et al 2015); once home, recall of past events is difficult and the person often has their story told for them by a relative or friend (Goldberg et al 2012). Additionally, the views of people with dementia can be negated as the structure and content of their conversation does not flow and can come in fragments (Sabat 2001; Hydén 2018). People are labelled as deficient (or in healthcare environments "confused"), they are not listened to, and stories are made up about them.

Research therefore becomes exclusionary when data collection methods rely heavily on intact verbal skills and good memory recall, which are known to deteriorate with dementia (Bartlett and O'Conner 2010). Qualitative studies often focus on people who are able to narrate their stories along the classical temporal and contextual lines, and there are therefore few studies that take into account the perspectives and experiences of people living with dementia when they become patients in hospital (Dewing and Dijk 2016). Additionally, Bartlett and O'Connor (2010) argue that research that privileges methods that limit or discount the power of the voices of people with dementia need to be challenged. However, very few researchers have analysed spontaneously produced narratives by persons with dementia, that is, narratives told around a self-selected topic rather than one suggested by a researcher (Hydén and Örvulv 2009).

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Research, and research practices that constrain participation can thwart the advancement of theory; hinder practice improvement, and compromise the quality of life of people with dementia (Symonds et al 2018). This is because the development of theories, and the associated clinical and care practices, require approaches that constructively provoke beliefs and assumptions rather than identify issues, which itself is largely based on the assumptions of others (Symonds et al 2018).

To help address this issue and to include more people in dementia research, Dewing (2002) argues for the development of dementia specific interview methods. However, I would argue that to be inclusive interview methods should not be used as these involve unidirectional questioning and recall on demand. Instead we should utilise narratives that are led by the person, and are in the context of that which is being explored; where the listener is attentive to a person's words and looks past the surface structure to enable a person with dementia to actively and constructively engage in conversation (Sabat 2001).

Fundamental to the ethos of this study is the right of people living with dementia to be involved in a research study if they so wish, and to use methods that are enabling and inclusive rather than disabling and inaccessible. Therefore the study utilises the EXPECT framework (Bartlett and O'Connor 2010), whereby we must EXPECT that men and women with dementia should be actively involved with the generation and translation of new knowledge, if they so wish. Bartlett and O'Conner argue that even in debates about inclusionary methods, the assumption has been that improved standards of care will be the outcome. Whereas this is an understandable stance, focusing on care prevents a move towards an understanding of people's lives and personhood. The EXPECT framework promotes the privileging of people's stories, extends the research agenda, uses participatory methods and approaches, addresses ethical debates and dilemmas, uses a critical lens and ensures that research is implemented in practice (Bartlett and O'Connor 2010).

Data creation for this study, whilst remaining true to a constructionist paradigm, needed to employ methods that were acceptable, accessible, and did not place the participant in a disadvantaged position. In numerous conversations with older people both with and without dementia, the aspect of being in hospital that was often cited as enjoyable (albeit rare) was having a conversation with someone who was not in a rush, and who truly listened. For me as a listener the narratives both verbal and embodied, that I have been privileged to hear fascinate me. I decided to explore the stories of (im)mobility of people living with dementia whilst they are an inpatient on an AMU by using unstructured conversations and observations made whilst undertaking these interactions.

## 5.2 The research questions

Chapters Two, Three and Four set out the background behind this study and from which the following research questions were formulated:

1. *What narratives are shared by a person with moderate or severe dementia in social or medical crisis when they are an inpatient on an acute medical unit?*
2. *Does a mobilities lens help in the understanding and interpretation of these narrative?*
3. *How can people with moderate or severe symptoms of dementia be enabled to contribute to the research agenda on acute hospitals?*

## 5.3 Constructionism

A constructionist paradigm views reality as relative to those experiencing it and that the complexity of human existence ensures that experience is created, shaped and constructed through social interactions and individual interpretation (Denzin and Lincoln 2013); people create their social world through interactions and relationships. Constructionism considers that our construction of the reality around us relies on our previous experiences that provide a framework into which current experiences can be placed and understood. When we find ourselves, perhaps through travel, perhaps through a life experience such as illness or bereavement in a culture or environment that is unfamiliar to us, we observe and evaluate. We compare against our cultural norms and previous experiences which we hold inside us as memories. We discuss with others and begin to understand and move within this new place. Gradually the newness becomes normal, we come to terms with and assimilate our new place into our internal world and eventually feel comfortable again.

With particular relevance to this study, constructionism recognises that knowledge is constructed through our lived experiences and through our interactions with other members of society (Lincoln et al 2011) and that reality is deeply personal. An understanding of reality therefore also requires an ability to understand and be understood, and to form relationships with those around us.

But what happens if we are not able to hold on to our short term memories, and memories of the past are becoming increasingly difficult to access? How then are new situations experienced, evaluated and assimilated? How is reality then constructed? What happens if the language we use is not understood, or misunderstood by those around us? For someone with dementia the

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framework within which they can construct a new reality in an unfamiliar situation becomes broken. Their reality can become this present place in this particular moment of time.

Everyday realities are actively constructed in and through forms of social action (Holstein and Gubrium 2011) such as conversations and narratives. These interactions are based upon social meanings such as beliefs, values, rules and motives, the interpretation of which vary from person to person and shape their reactions (Goffman 1967; Hammersley and Atkinson 2007). The result of this is that the same physical stimulus or environment can mean different things to different people, or to the same person at different times. Within each moment there are multiple interwoven interpretations of reality. This research takes as its premise the understanding that peoples' narrative practices are shaped by, and shape, their narrative environments and that through their narratives their reality in that moment can be understood. Holstein and Gubrium (2011) describe this as a reflexive interplay. They argue that to understand narrative reality requires attention to both the narrative environments and to the narrative practices that are employed.

This study does not aim to generalise to entire populations but to the social processes that are inherent when healthcare is provided to, and experienced by, people with dementia when they are in the hypermobile environment of an AMU. Whereas many studies have relied on participants verbalising their own story via interviews or other forms of verbal communication (Hammersley and Atkinson 2007) an approach that privileges the articulate; this study uses narrative enquiry to include people with dementia in unstructured conversations and interactions; purposefully looking beyond the mere verbal for layers of meaning that are conveyed by different modalities. This narrative may be contextual or non-contextual, temporal or not time related. It may be spoken or unspoken. However, in order to understand a person an approach is needed that gives access to the narrative behind these communications, and this clearly requires interpretation by the researcher. To assist with this interpretation, it was important that data was collected on the AMU so that the person was able to express themselves in the context of that environment.

Whilst it is acknowledged that it is impossible to fully understand another persons' experience, especially if that person is living with a condition that we do not have, what people say or communicate can be taken as evidence of their perspective (Hammersley and Atkinson 2007). Therefore this narrative enquiry explores the verbal and embodied narratives of people whilst they are inpatients on an AMU.

Inherent to the structure of this study is the interpretation of another's narrative. In the context of this research study, the constructionist paradigm requires that I must take into account my

own values, beliefs, history and commitments. I am a physiotherapist and advanced clinical practitioner who works periodically on the AMU. Despite conscious effort I view all interactions through the lens of a professional who is “adapted” to the rules and motives that underpin daily life on the ward. The suspension of my pre-conditioning has entailed fore fronting this knowledge during data collection and analysis and being aware of how this has affected the collection and analysis.

Equally, people with dementia arrive in the AMU with their own presuppositions, experiences, beliefs and cultures through which to interpret the happenings of the unit. Interpretation of reality thus becomes a joint endeavour; there is no one definite shared reality. Unlike most medical encounters there is no right or wrong answer; all narratives can be considered as truth.

Thus this study utilises a *layered* approach to understanding and analysis whereby my initial impressions and feelings are explored, followed by a deeper analysis of the individual stories and a search for commonalities between the narratives.

## 5.4 Narrative Enquiry

*“You can’t walk in my shoes, and I can’t walk in yours. It’s my life not yours – please listen to me”.*  
(Linda. Alzheimer’s Society Conference May 2018)

Narrative is necessarily an ambiguous term that revolves around an interest in life as narrated by those who live that life (Chase 2011). Narrative can refer to the process of making a story, to the cognitive scheme of the story, or to the result of the process (Polkinghorne 1988). Meaning that narrative is the story being told and also the telling of the story. We create narratives for ourselves and for our listeners; they enable us to define our sense of self and what is important to us and what makes us who we are. Narrative “expresses the uniqueness of each person and addresses the listener, not as a professional, but as a fellow human” (Hurwitz et al 2004 p4).

Narrative enquiry is a way of understanding experience; it involves the reconstruction of a person’s experience in relation to both other people and to their social world through the stories that they tell (Pinnegar and Daynes 2007). People shape their daily lives by stories and interpret their past in terms of these stories; narratives are therefore a way of thinking about our experiences and making sense of them in our ever changing world (Clandinin and Rosiek 2007). What is researched, and who the researcher is, emerge in the narrative interaction, making this a dynamic process inside which growth and learning can occur. (Pinnegar and Daynes 2007).

The classical conceptualisation of narratives is linear - they might swing back and forth in time and place, but they have a beginning, middle and ending that together are constructed by the teller

and the listener into a coherent whole (Yorke 2013). In everyday life we recount stories through which we both represent and construct ourselves to the listener (Baldwin 2006). As we narrate a story to a friend about something that is significant, we do not just recite a list of the events; we glue the events together by referring back to previous events and experiences both consciously and unconsciously (Goffman 1990). We rely on a basic instinctive understanding of each other's social characteristics which can leave much unspoken but nevertheless acknowledged (Goffman 1990). Thus, stories are co-constructions of events that include feelings and thoughts and involve interpretation. Goffman talks of the interaction order, where face to face contacts are socially (if unconsciously) organised, in much the same way as a drama is performed on stage. The better we know another person, the easier it is to tell our story and for the listener to understand it and understand us. Society is organized on the principle that any individual who possesses certain social characteristics has a moral right to expect that others will value and treat him in an appropriate way (Goffman 1990), and one way that this is demonstrated is through conversational interactions such as turn taking and the mutual co-construction of narratives.

Narratives can convey not only experience but also who we are – our sense of self. In a constructive conversation the listener and the speaker interact in a form of performance, where each takes a role and supports the other in theirs; the listener finds that through this performance they are able to understand who their conversational partner is (Goffman 1990). Thus part of the expression of our identities to others is in the way that we tell and perform stories about our past. Although over time the finer details of these stories may change, the overall coherence of our life stories as we relate them to others remains unchanged and stable. As listeners we become uncomfortable when someone's story is not logical, temporal and linear; or when the story changes each time that we listen. If we cannot easily establish the storyteller's identity, or cannot place them in our world order and remain unable to categorise them, we are left with feelings of uncertainty. It becomes difficult to develop a social connection. Communication breaks down and in the words of Baldwin (2006) the narrator becomes "narratively dispossessed".

This subtleness of communication is significant when related to someone with dementia who may not interpret other's signals, and may no longer be able to provide the instinctual social signals that allow a face to face interaction to be constructed and understood. When the interactional components of a conversation are misunderstood, we are left in a place of mutual misunderstandings. If we cannot understand the signals that help to complete a narrative, we are left unable to establish Goffman's (1990) "what is" and thus have no foundation upon which to build a relationship, or value what and who the other person is. As Goffman proposed, people are less ready to see that few impressions could survive if those who received these impressions did not exert tact in their reception of it. However, to exert this "tact" and to allow impressions of the

other to survive we first need to be able to understand a person when their way of informing us varies from our sub consciously recognised culturally acceptable norms.

With direct relevance to this study, Riessman (2008) discusses how form can follow function in a narrative and that “the investigator can interrogate what the narrative accomplishes and precisely how the form of telling achieves that end”. She recognises that there are many ways to tell of an experience and that personal narratives can contain performative (or embodied) features as well as words. Riessman also recognises that narrators can position themselves socially within their stories and take on a variety of roles. This becomes particularly relevant when considering a person who during a conversation may fully believe that they are a child, parent, sibling or worker for example, not for the purpose of telling a story, but because that is their reality at that particular moment in time. Finally, narrative enquiry can help to counter the tendency to understand people who have dementia as a group who are defined by their diagnosis, rather than by their lived experiences, and to acknowledge that dementia is an interruption to a life story, and not the whole story (Capstick 2009).

Within the positivist bio-medical research model that prevails within healthcare systems, personal narrative has traditionally been considered at the lowest levels of clinical evidence, where superiority is given to randomised controlled trials. When the subjective experience is considered it is the voice of the coherent narrator that is privileged; the voice that most clearly fits the world and cultural models of the professional listener (Bartlett and O’Connor 2010). Where narrative is used within healthcare it is understood as “a meaning structure that organises events and human actions into a whole, thereby attributing significance to individual actions and events according to their effect on the whole” (Polkinghorne 1988 p18). What chance then for a person who does not organise their narrative into a meaningful structure to have their narratives acknowledged? Opportunities for narrative expression become limited, and people living with dementia may experience a loss of control, in that decisions are made for them (and stories made about them) as they are increasingly defined as lacking capacity (Baldwin 2006).

Within acute hospitals the stories of people living with dementia have been colonised by others, rather than being considered as people who have narratives of their own. Healthcare staff seek the biomedical narrative that will lead to a diagnosis, treatment and discharge; researchers use their questions and observations to look for the narratives they need in their research. The person with dementia becomes an “excluded voice” (Booth and Booth 1996).

This study takes as a fundamental premise that it is the right of people with dementia to have their subjective and experiential realities taken into account, to be heard and to participate in

studies in which they are expert. This has presented practical, ethical and creative challenges and has involved using methods that are new to the acute hospital environment.

## **5.5 Data creation: privileging people's stories**

The stories that I heard people tell whilst working clinically had a strong visual component. Some stories involved no words at all; simply movements, facial expressions and touch. Their stories were embodied. I therefore wanted to use a data creation method that could capture this embodied language as well as capture words. I decided to use videos.

I discussed my idea of videoing conversations using a tablet that could be played back to the participants for context and comments, with people living with dementia and their relatives during discussions that I had prior to the start of this study. The idea was well received so I trialled the use of a tablet in my clinical work in the hospital, to look at movement disorders, and found that the use of video in this form was enjoyable to the people who took part and acceptable to staff. I discovered that people were clearly able to tell me if they wished to take part in a movement disorder video or not, and the resultant videos have proved to be a valuable teaching resource.

I trialled the use of the tablet with my ever willing parents (both age 85+) and found that they too found it enjoyable. They also agreed to let me use their videos to show potential participants to enable contextual conversations around what making a video together entailed.

The tablet I chose to use was a Samsung Galaxy S3 which has a large 9.7 inch screen and good picture resolution which I hoped would be visible to people without perfect eyesight. It was also very simple to use. In order to make videoing easier it had a case with a stand so that it did not need to be held during conversations. In addition to the videos I used field notes of participant observations and to add contextual information to the recordings; and audio recordings.

I worked with the hospital medical photography unit, communication department and Medicine for Older People and Acute Medicine consultants to ensure that any prospective video recordings met with Trust policies and guidelines. I also met on several occasions with the AMU matron and senior nursing leaders on the AMU to ensure that they were happy for me to be present on the ward making videos. I had expected to meet some resistance, but all the staff that I spoke to were happy for me to make videos of people with dementia whilst they were inpatients on the AMU.

A major consideration was that data was collected whilst participants were still inpatients on the AMU. I had previously undertaken a Masters in Clinical Research which explored the experiences of older people after a rapid discharge from an AMU. In that study I interviewed participants at

home a few days after discharge. I found that older people, both with and without cognitive impairments, were not able to remember their brief stay in hospital in any detail. Where relatives were present they tended to take over and tell the admission story from their perspective. I did not hear the same stories in these interviews that I had heard from other people whilst they were inpatients on the AMU; I began to recognise that the context of the data collection is a key factor. It is known that there is limited research that explores the acute hospital environment from the perspectives of a person with dementia, resulting in their voices being silenced. It was important to me to enable people to tell of what was important to them, in that place and in that moment.

This study was designed to enable people with dementia to share their narrative with me. It was therefore important that I did not use an interview guide or ask non-contextual questions because this would have directed the conversation towards my narrative – that of a clinician/researcher undertaking a PhD.

Narratives can develop understanding that is grounded in experience and can stimulate reflection and generate new ideas (Hurwitz et al 2004); this study focused on what was contextual and important to the participant at the time of our interaction. Patient narratives can also be a powerful way of improving patient care (Wilcock et al 2003). However not all people with dementia are able to verbalise their stories in a temporal and linear fashion so spending time together allowed open-ended interactions, interpretation of body language, conversations and observation of reactions to specific clinical events and other people on the ward.

Booth and Booth (1996) recognised that researchers should put more emphasis on overcoming the barriers that impede the involvement of inarticulate subjects in narrative research instead of dwelling on their limitations as informants. This study focused on what the participants' could share in terms of narrative, rather than what they could not. One of the strengths of using video was the wider range of response possibilities that were captured that extended beyond the narrow range of verbal responses (Prosser 2013). Additionally, Dewing (2002) argues that it is not simply listening to a person but the attentiveness of the researcher to what is being said which is crucial, and that this can transform the process of data collection into a potentially therapeutic process.

Unlike other illness narrative explorations (Frank 1995; Hurwitz et al 2004; Charon et al 2017) I did not ask my participants about their illness either acute or longstanding. I was primarily interested in what my participants talked about and how they conveyed information in that moment. The collected stories are necessarily fragmented and represent only one short moment in time, but in reality this is how most clinical encounters are framed - short interactions with different healthcare staff.

Data were collected in two week blocks with a period of reflection and analysis in between each block. I used this iterative approach because I could find no other examples of this type of study based on a busy and pressurised environment such as the AMU. I used the gaps between data collection to review my recruitment and consent processes; reflect on the ethical and moral aspects of including people in medical or social crisis and to start analysis before the end of data collection.

## **5.6 Participatory methods: Using video**

This study captured the narratives of people by using video. Participatory videos made with and by people who have dementia have been used to empower people to tell their own stories and to enable people who work, live and socialise with them to listen (Capstick 2009, 2011, 2012; Capstick et al 2016; Alsawy et al 2019). However this other research has taken place in long term care facilities and in the community but not within acute hospitals (Symonds et al 2018).

Videos are increasingly being used in our social lives using hand held devices such as phones, and made publicly available on social networking platforms. People are allowing their private lives to become public. Within hospitals, television film crews are now regularly making documentaries and accessing people during what are often traumatic or emotionally disturbing events. However, despite the increasing use of video in qualitative research in general, the use of video for research within hospitals is uncommon.

Hung et al (2017) used “go along” interviews with people with dementia, as part of a project to improve the ward environment from the perspective of the patient. The environment of the ward was experienced together, and the person did not need to rely on recall; any questions asked were contextual. The findings from the videos were used by ward staff to change the ward environment. However, although the videos also captured non-verbal expressions, these were not discussed within the context of the published paper.

Likewise, Symonds et al (2018) used video reflexive ethnography in an acute hospital unit to understand what organisational behaviours were contributing to good quality care. The methodology was designed to be inclusionary, but the person with dementia was still firmly placed as a care recipient upon whom care practices were performed and then critiqued by healthcare professionals.

Video can capture a wide range of response possibilities allowing a greater depth of data to be collected. Additionally the audio-visual materials that are produced can be commented on by participants to produce a further layer of knowledge (Pink 2013; Symonds et al 2018) and help

create meaningful participation in data creation. In this project visual methods are used to capture the sense and experience of movement and mobility of the participant, the researcher and of the ward around them; as well as the communication that happens between the participant, the researcher and others.

Visual methodologies can make a major contribution to research by adopting an egalitarian stance by working alongside the most vulnerable, underrepresented, and least researched and understood members of society (Prosser 2013) – in this case people with dementia. People with dementia are habitually excluded from research because of the assumption that they are insufficiently articulate to either consent to participate or contribute through interviews or survey samples (Prosser 2013). One of the strengths of visual research is that it can record a wide range of possible communication strategies and reveal important information that text or word-based methods cannot (Prosser 2013).

However, recognition is needed that visual practice and its products embody a complex meeting of the cultures of the depicted and of the depicter (Pauwells 2010) and are not a simple visual representation of reality. It is therefore necessary to work reflexively and to also document significant contextual information; analysis of the making of the video and inclusion of the participant's reaction (Pauwells 2010) to the film. Thus the use of video can be a collaborative and reflexive exercise that is undertaken by both the researcher and the participant to produce knowledge. Its value in the context of this study is that it can capture not only audio language, but the embodied language of the participant. Additionally it creates contextual data that can be reviewed and discussed with the participant; kept or discarded as they feel appropriate. Thus giving meaning to Pink's (2013) assertions that the ways that images are interpreted and given meaning are culturally and biographically specific and do not tell of one truth.

As Pink (2013) argues, videos do not necessarily take on the status of being knowledge or findings in themselves, but rather can be understood as routes and tools through which to gain knowledge and encounter other people's worlds. They can be utilised to help interpret how people constitute both their self-identities and place through their multisensory embodied experiences (Pink 2007). She also suggests that by using visual methods the assumption that the researcher can know another person's mind through an interpretation of only their words is challenged. However, Pauwells (2010) lends a cautionary note with his observation that all knowledge is "work in progress" and is incomplete and dependent on the perspective of the viewer.

Unlike previous studies where small digital cameras have been used (Capstick 2011), or video equipment (Hydén and Örvulv 2009), in this study I chose to use a tablet. The use of a tablet, rather than a camera, to make the videos was carefully considered in order to facilitate the participant to

review their videos instantly on a reasonably large screen, and to bring the data to the participant in a meaningful way. It also was very simple to use and hold, my aim being to enable people to video their immediate environment, or me, if they so wished. The ability to review the video after filming also enabled people to have a more contextual understanding of what the research was attempting to achieve, to decide whether to keep the video, and to enable people, where possible, to consent for themselves.

Using video within an acute medical unit to record people affected by dementia when they are in medical or social crisis raises significant ethical and moral issues. These are addressed in detail in section 5.11. However, as the use of videos in this setting is novel, it is also important that practitioners of visual research reflect and report their experiences in order to ground their situated ethics in reality (Prosser 2008).

An additional concern for me was around collecting data as a researcher in an environment where I am at times also a clinician. I am habituated to viewing the hospital world through the lens of a clinician. The use of video can theoretically add to the reflexivity of data collection by producing a view of the interaction that is independent of the researcher's, and therefore produces a more neutral perspective which is less susceptible to "insider" bias at the time of collection (Prosser 2013); equally if viewed with the participant at the time of recording the power imbalance of researcher/researched can (theoretically) be somewhat addressed (Prosser 2013).

One participant did not wish to be videoed and this narrative was captured as an audio recording. Immediately afterwards I wrote my field notes to capture his movements, but I was not able to capture from memory the finer, nuanced details of his facial expressions and micro movements.

### **5.7 Setting**

Participants were recruited from the AMU of the NHS Trust for which the researcher works. This is a 54 bed unit, divided into 4 sections, with a rapid turnover of patients over the age of 18, who usually stay for less than 72 hours. Three of the sections are joined together in a line, with the throughways between them running between the bays on one side, and the beds around the work station on the other. These throughways link together, effectively making one long corridor which is used by many people as they move between parts of the unit. The doors between the sections are therefore usually left open to enable easier access along the corridor. The fourth part of the unit is smaller and is not part of this long, internal throughway and therefore sits slightly separately. The three larger sections are arranged around a large multidisciplinary work station. Patients who need to be more closely monitored, because they are critically unwell or at risk of

falling over, are placed in beds which open directly onto this work station. There are also a number of siderooms that open into the general area.

The AMU is a busy, noisy area where people with medical problems are transferred from the emergency department, if they are not admitted to a speciality ward or discharged. People present with many different problems such as infections; drug or alcohol problems; injuries from falls or overdoses. There is a constant turnover of patients, and different medical and surgical teams visit and review the patients throughout the day. Relatives visit, sometimes en masse, and in addition to medical and nursing staff there are healthcare assistants, pharmacists, physiotherapists, occupational therapists, social workers, domestic staff and bed managers. People move constantly along the throughways between sections of the unit.

Extensive field notes were made of observations of life on the AMU. I observed staff, staff interactions with patients, and patients who were either with or without relatives. I visited the AMU to collect data at different times of the day and at weekends as well as weekdays; aiming to capture narratives across the weekly rhythm of the unit. I recorded two soundscapes to ensure that when I was away from the unit transcribing and analysing my data, I could refer back to the actual noise that accompanies life on the AMU. Additionally, I also recorded my thoughts and feelings as I attempted to collect data.

Data were collected over a six month period. During this time twelve participants were recruited to the study. Nine videos were recorded, one audio recording and two participant observations were written up as field notes.

Ethical approval for the study was received from the University of Southampton and the NHS Health Research Authority, South Central – Berkshire Research Ethics Committee [REC], reference 17/SC/0625.

## **5.8 Recruitment**

This research involved collecting data from people living with dementia on a very busy unit with a high turnover of patients, therefore the process of recruitment and consent had particular ethical and moral issues that needed to be addressed. This type of study has not been done before in this setting and recruitment and data collection required significant planning and thought.

Before the start of the study I met with senior ward staff such as nurses, consultants and therapists to discuss the aims of the study and what types of data collection were planned. Although I had anticipated some resistance, my plan was positively received and senior staff gave

their authorisation for me to proceed with gaining ethical approval and going ahead with the research.

Due to the short length of time (12 – 72 hours) that each participant remains on the AMU the processes of recruitment and consent to participate presented specific ethical challenges, as the time to think about whether or not to be involved was necessarily short as patients can be moved quickly from the unit with little notice.

This study utilises the EXPECT framework (Bartlett and O'Connor 2010), and as such central to its aims are the inclusion of men and women with dementia on an equal footing as those people who do not have dementia. The ethos of using inclusionary methods becomes problematic when our research processes, such as recruitment and consent to participate, rely on a person being able to understand complex written and verbal information and to be able and willing to sign forms. My previous experience during my Masters in Clinical Research study had been that many people were put off participating when I produced a complex and detailed participant information sheet, and a consent form that required several signatures. For a person with dementia who may want to take part in a study, this is a high hurdle to cross and sets the person up to fail. Dewing (2002) contends that cognitive competency based approaches to informed consent make the process existentially threatening to a person with altered abilities in communication, memory, language and perception. Researchers have been too ready to accept the bio-medical construction of informed consent and thus slow to develop viable alternative methods acceptable to ethic committees (Dewing 2002).

### **5.9 Inclusionary consent**

This study involved an activity that my clinical experience had shown was an enjoyable distraction from the noisy, busy and stressful environment of the AMU – namely an unhurried conversation. I also knew from making videos for movement disorder teaching, that using the tablet could also be a welcome distraction for patients. Even when people did not want to let me record them, we could pass time together surfing the internet or looking at photos. The juxta-positioning of making a clinical video and making a research video was not lost on me. As part of my clinical role I had made videos of movement disorders to be shown in a workshop that I held at the British Geriatric Society Autumn Conference in 2017. Clinically I asked the consultants, the senior nursing staff, the medical photography department and the communications department of the hospital if I could make the movement disorder videos. This permission was granted with the condition that the person in the video signed a simple hospital consent form (Appendix G).

This contrasted strongly with the normal process for gaining consent from a participant in a research study. In practice, informed consent is a one off process that involves the researcher providing a detailed participant information sheet that provides amongst other things the purpose and background of the study; what taking part involves; benefits and potential risks; what happens when the research stops; confidentiality; the consent process and how data will be stored. This textual document runs to several sides of A4 and is inaccessible to all but the most uncompromised of participants. It is followed by a consent form that asks for consideration of multiple contingencies including confirmation that the information sheet has been read, that their participation is voluntary, that medical notes may be accessed, and that they consent to participate. In studies such as this one, where people with dementia are included the use of such complex paperwork can become exclusionary. Whereas some people may be able to fully participate in this type of consent process, the person with altered abilities in communication, memory, language and perception does not experience this ritual of informed consent from the same perspective as a cognitively competent person and will find the process overwhelming (Dewing 2007; personal experience). The more I reflected, the more I recognised that this process was designed to protect the researcher rather than the participant, and left a person affected by dementia in a position in which it is almost impossible to consent for themselves, and therefore dependent on the decisions of a consultee. In terms of Kitwood's (1997) malignant social psychology, the person becomes outpaced because the information that is provided is too complex and in a form that is difficult to understand.

There is increasing unease amongst qualitative researchers that the ethics process in research is exclusionary rather than inclusionary (Dewing 2002, 2007; Bartlett and O'Connor 2010) and based around the ethics and consent processes that are designed for clinical trials. This has caused ethics review boards to be tied to the experimental, hypothesis-testing positivist paradigm (Denzin and Lincoln 2013). This, argues Dewing (2002) leads to exclusion of older people with dementia from research due to the complexity of the consent process, and thus increases their vulnerabilities as they are under-represented in research. She calls this "exclusionary ethics" whereby the duties and action of others (the researcher, ethics committees) are prioritised.

Therefore I argued strongly at the Research Ethics Committee (REC) meeting against using the participant information sheet (PIS) (Appendix C) and consent form (CF) (Appendix D) that I had produced for the purpose of gaining ethical permission to undertake the study. If a consultee was involved I used the consultee information sheet (Appendix E) and declaration form (Appendix F). I argued that a one off consent process that was very complex did not, in my view, enable the participant to properly consent; and that if the process was simplified then more people would be able to consent for themselves. I also proposed to divide the consent process into two parts:

firstly to take part in a conversation, and secondly to use the resultant video or audio recordings as data for research and for showing in educational settings such as teaching or conferences. The REC agreed with me:

*“The Committee agreed that current patient facing documents, including the PIS and CF, could be used as a checklist for the researcher rather than being given directly to participants. It agreed that process consent was more effective than the use of a CF on a single occasion. It noted however that clear records of ongoing explanation and consent should be kept – perhaps in the form of a reflective diary which should be used in the context of ethnography in any case. The documents should still be used for consultees”.*

*“The Committee said that there was no doubt that the research was connected to the impairing condition and it was a rare example of research which targets this group with an aim of understanding them better. There was, as well, an ethical imperative to conduct research of this nature as it should also yield some useful training materials and might lead to positive changes in practice”.*

Simplifying the consent process in this way and using process consent throughout the interaction resulted in more people with dementia being enabled to take part in the study and to consent for themselves. However, to conform with the Trust regulations each participant (or proxy where appropriate) did sign a simple hospital consent form that confirmed that they were happy for the video recording to be used in either research, education or both.

### **5.9.1 Process consent**

Dewing (2007) has proposed the use of process consent. This form of consent was developed to enable the inclusion of people who may not be able to consent to participate using the one off written informed consent process that is commonly used when recruiting a participant into a research study. Dewing (2002 p158) contends that the “continued adherence ..... to the traditional approach and methods based on a universal system of ethics grounded in responsibilities and rights is not consistent with research that is said to be person-centred and that therefore values personhood”. To counter this Dewing (2007) proposed a 5 step process consent model:

1. The researcher is transparent about her intentions; knows something about the person and includes others who are significant to the person with dementia if appropriate.

I addressed this by using the tablet to facilitate a contextual conversation around what taking part in this research study would entail, and what the output would look like. This was an unhurried conversation during which I told the potential participant about myself, showed them pictures of my family and listened to them talking about themselves. Where a relative was present they joined in. I clearly introduced myself as a researcher and wore a “researcher” label; additionally I was not in a uniform to distinguish myself from clinical staff.

2. Capacity and other abilities is established - I have had extensive clinical experience of establishing the capacity of a person to make specific decisions using the principles of the Mental Capacity Act (2005); and am able to recognise that capacity is situational and variable and is communicated in a variety of ways; and that recognition of how the person is in that moment is important.
3. Initial consent – I provided contextual and accessible information which was verbal and visual to enable the person to make their own decision about whether to participate in the proposed research or not.
4. On going consent monitoring – I checked throughout the time I spent with a person that they were happy to continue, and stopped if they wanted too or became tired. If during the time spent together it became apparent that the participant did not understand the non-contextual concept of using the data in research or education, then I deferred to a personal consultee for their opinion as required by the Mental Capacity Act (2005). I did not use a professional consultee as it was important that the consultee had a close relationship with the person.
5. Feedback and support – feedback to relatives and staff can be made if carefully considered and appropriate; however the rights of the person to confidentiality must be foregrounded. Equally consideration should be given to whether the person requires support to transition back into their environment after the research encounter is ended.

Dewing also recognises that the ability to demonstrate this type of reflexivity in the field is central to the process consent method, and this may be challenging for novice researchers to achieve. Thus the method may not be suitable for use by less experienced researchers or those who have little experience of working or socialising with people who have dementia. According to Dewing, the process also relies on the skill and expertise of the researcher in being able to engage with persons and being able to critically reflect on their own actions.

I also discussed this process with others. The lead Admiral Nurse (dementia specialist) in the Trust was clear that people affected by dementia should be enabled to make decisions for themselves, and that often people were infantilised and decisions made for them and about them. One of my concerns was that a person may not remember that they had given consent, taken part in my research and potentially made a video. The Admiral Nurse was clear that if a person understood and agreed to take part, that if the information given was accessible, if there was not coercion and the person was treated with dignity and respect, then their decision must be recognised and adhered to. Additionally the Mental Capacity Act (2005) states that:

*“The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision”.*

I also discussed and debated the concepts of process consent and capacity to consent with other clinical academics who are also working in the field of dementia research. The foundation of making an ethical and moral decision that protects a person whilst also empowering them is not easy or at times even comfortable; however at the heart is an individual with a diagnosis of dementia. And it is this individual who, in my experience, if their subjective and experiential realities of their present situation are taken into account, can usually make their own decision.

An additional concern was whether people felt enabled to say “no”. I had several occasions where people declined. One man when approached by a therapist to see if he would like to take part, closed his eyes and disengaged; another lady said she would like to hear more but when I explained the study she said “no I don’t think I do really” then quickly added “I’ll think about it”. For some reason (which could have disempowered and negated this lady) I asked if I should consult her daughter - “No. It’s about me, isn’t it? I make the decisions”. It seems that people were as comfortable saying “no” as to agreeing to take part.

## **5.10 Inclusion and exclusion**

Once ethical approval was obtained, dates and times of data collection were regularly provided to the senior ward management team so that staff could be informed. Additionally, each time I visited the AMU to collect data, I checked with the senior nurse in charge that this was acceptable. I then informed the nurse in charge on each part of the unit who I was, and what I was doing.

Initially I planned that every patient with a diagnosis of dementia would be given a leaflet explaining the study. However, after discussion with the REC I reconsidered this strategy, as some people may be unaware of their diagnosis and others may be unwell or upset. It was agreed that people should be screened beforehand. Therefore, I gained permission from the trust Caldicott Guardian<sup>3</sup> to review the notes of all people with a dementia diagnosis who were on the AMU. In this way I could ensure that I did not approach people who were critically unwell or approaching the end of their life. The drawback to this approach was that on first meeting each participant I knew their clinical history and their diagnosis. This meant that I knew them as a clinician first,

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<sup>3</sup> A Caldicott Guardian is a senior person responsible for protecting the confidentiality of people's health and care information and making sure it is used properly. All NHS organisations must have a Caldicott Guardian.

creating an entanglement of my clinician/researcher identities that was at times difficult to ignore.

I then asked a clinical member of staff to approach the patient, tell them about my study and ask if they would like to find out more.

Patients were eligible to be included in the study if they:

- Had a diagnosis of dementia either with or without an overlying acute delirium
- Were not critically unwell and not receiving end of life care. The status of critically unwell was determined by whether or not the critical care outreach team was involved with their medical management, this was established from the notes. Palliation was also established from the medical notes.
- Were able to make known and communicate their choices and preferences either verbally or non-verbally. This was established by discussion with a clinical member of staff.

If the patient indicated that they would like to meet me, I used the patient information sheet as a prompt for me to discuss the research. At the same time I used the tablet to show pictures of me and my family, and to show a conversation between me and my parents. I believe that if I am asking a person to give something of themselves, then I should be open with them too and give something of myself back. I believe that this also gave the person (and relative if present) a clearer understanding of what the study entailed and therefore enabled an informed decision to be made around participation. This did not always lead to the person participating, or to the use of the video, but did enable some enjoyable conversations.

## **5.11 Ethical considerations in visual research**

*“Visual researchers cannot afford to sit on the sidelines when ethics are debated, but should think through and argue their ethical position” (Prosser 2008 p11).*

People with dementia have been a marginalised group within acute care provision, and as demonstrated in previous chapters, much past research in acute hospitals has excluded people who are unable to consent for themselves or participate in interviews or surveys. As a result, there is limited understanding of how acute care impacts on a person with dementia. It is fundamental to the ethos of this study that the voices, both embodied and verbal, of people with dementia who are receiving care are heard, and that their inclusion in this study is based on sound ethical principles.

## Chapter 5

Dewing (2002) recognises that all ethical decisions and actions are context-specific and are centred around relationships; by considering each person as an individual rather than attempting to apply a universal approach to ethical decisions, the principles of personhood, direct representation of interests, equality and social justice can be upheld. She additionally recognized that this leads to a person being able to make decisions for themselves and engage in co-operative participation.

However, there remains an ethical muddiness around the use of video (Puurveen 2015). In weighing the burdens and benefits of participation, an important question to ask is to what extent the images impact the reputations of the people represented, and to what extent they forward new knowledge (Puurveen 2015). I endeavoured to ensure that each participant looked dignified, and always asked if someone would prefer to be in bed, sitting in a chair or walking around. Only one participant chose to walk around his bed whilst being recorded, but as he did not want to be videoed, this was an audio recording and there was no visual imagery to consider. I helped some people into dressing gowns or cardigans if they so wished; for other people I covered them in a blanket if appropriate. I cannot control what an audience might interpret from the images that I recorded, but believe that I have upheld the principles of respect for my participants and doing no harm. All names were changed and if the name of the person was displayed above the bed this was rubbed out and replaced at the end.

Within qualitative research there is a blanket assumption of confidentiality and anonymity which, if unquestioned, will place visual research at a significant disadvantage (Prosser 2008). Visual images cannot be anonymised unless they are so pixelated as to render them useless. Visual methods, such as that used here, lend themselves to participatory approaches and in such contexts, participants may explicitly and voluntarily waive their rights to confidentiality and anonymity, contravening one of the cornerstones of normative ethical practice in social science research (Prosser 2008). My participants understood that they would be recognisable in the videos but that their names would be changed; the participant or their proxy decided if the recordings should be used for data only or also for educational use such as clinical teaching and conferences.

The ethical and moral dilemmas posed by inclusion, exclusion and capacity to consent (or not) have become increasingly imperative to me as I have reconsidered my research, clinical and personal worlds in the dawning light of the EXPECT framework as proposed by Bartlett and O'Connor (2010). This has led me to question labels that are commonly applied such as the term "capacity". What does it do to rights and empowerment when you are labelled as lacking this

attribute? And why is the ability to demonstrate agency and decision making denied to certain people?

### 5.11.1 The Mental Capacity Act (2005)

The Mental Capacity Act [MCA] (2005) is a law which aims to support and safeguard people aged over 16 who are considered vulnerable when making decisions about their lives. The MCA is central to the ethical foundation of this study as it is through this law that the assessment of the capacity to make a decision about participating in this study was made. The Act states that “a person must be assumed to have capacity unless it is established that he lacks capacity”. Capacity must be assessed in terms of a person’s ability to make a decision at the point at which it is required; and to enable this the five key principles of the Mental Capacity Act were adhered to within this study:

1. Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise.
2. A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
3. Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
4. Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests.
5. Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

Within healthcare there is common usage of the term “lacks capacity” (personal observation). I have heard this term used by consultants, nurses, therapists and healthcare assistants. The Trust within which this study is set makes it a mandatory requirement that all staff undertake e-learning on the MCA and capacity, yet this might well be a case of a “little bit of knowledge can be a dangerous thing”. The MCA and the issue of capacity leads to the division of “them” from “us,” drawing a line between the less forgetful and the most forgetful, thereby exposing people with dementia to a vulnerability manifest in disregard of their remaining capacities, subjectivity, and well-being (Post 2000) – they are put in a position whereby they can be deemed to “lack capacity” *in everything*. The MCA leads, in its simplest interpretation, to an either/or assessment. However all capacity should be assessed around only one issue, and at a time when the person is at their cognitive best.

During recruitment for this study on several occasions when discussing a potential participant with a healthcare professional, I was told that I would not want to consider this person as they lacked capacity. I used this as an opportunity to ask “*capacity for what?*” and discuss the MCA and how it should be interpreted as a means of enablement, rather than disablement and disempowerment.

## 5.12 The participants

Table 1 shows details of the participants who were either video or audio recorded. Two additional narratives were collected as field notes. Although nine videos were recorded, one was not included as the participant did not understand the concept of using the video for research or education and I was not able to obtain the opinion of a proxy despite several attempts to contact their daughter.

	Age	Acute condition	Video/Audio
<b>Albert</b>	97	Chest pain	Video
<b>Arthur</b>	88	Influenza	Audio
<b>Bert</b>	94	Respiratory infection	Video
<b>Brenda</b>	92	UTI	Field notes
<b>David</b>	83	Sepsis	Field notes
<b>Elizabeth</b>	82	Chest infection	Video
<b>Ivy</b>	101	Urinary tract infection	Video
<b>Jane</b>	84	Fall/Fractured hand	Video
<b>Philip</b>	83	Came in with wife. Not unwell	Video
<b>Roger</b>	76	Urinary tract infection	Video
<b>Rose</b>	94	Decreased use of left arm	Video

Table 1: Participants and recording medium

### 5.13 Transcription

Using video recordings of narratives led me to the question of how to undertake the transcription and analysis processes. Schwartz (2007) argues that in a world where we are surrounded by an ever increasing number of visual images, there is an assumption that we have all become visually literate – that we know how to “read” a picture. She suggested what I was feeling - that viewing images is not intuitive but is a skill-based activity that differs from language, and is in fact a fundamentally different communication system that does not lend itself to context-free semiotic analysis. Schwartz’s (2007) essay also highlighted another problem for me: the videos that I recorded and the meanings they conveyed were at risk of being demoted to a secondary, illustrative role, with attention focused on the written arguments I built from the images. Notwithstanding, I still needed to transcribe what I saw on my videos into words that could be represented in this written thesis.

I did not find a pre-existing method of transcription that seemed to fit both words and pictures, but I remained aware that it is in the process of transcription that embodied voices are often rendered mute and are lost to analysis and/or interpretation (Chadwick 2017). Once I started to look attentively, however, each video lent itself to its own form of transcription, excerpts of which are shown in the findings chapters.

Each video represented a short, arrested moment in time that the participant kindly allowed me to share. After viewing each video 3 or 4 times, I realised that these images could be viewed through the lens of mobility and immobility that was central to my thesis, and that this would necessitate the observation and recording in words of the movements, and importantly to this research, the micro movements that were made by the participants. These were then added to the transcripts alongside the spoken words. This meant that the transcriptions needed to be re-thought as open and sensory texts, rather than closed, realist and empirical reflections of simply the words (Chadwick 2017).

Narrative enquiry is grounded in auditory, kinaesthetic, and aesthetic sensitivities (Bresler 2006) and therefore if narratives are viewed solely as texts, consideration of these elements is prevented. Utilising a lens of mobility enabled an understanding of the narratives which was beyond solely the auditory. Additionally, for people with dementia narratives should be treated as a collaborative and embodied activities which go beyond the words to the enactment and performance of the story, enabling the discovery of new aspects of social interaction (Hydén 2008, 2013). Thus the movements that each participant made were considered as an integral part of the narrative.

I originally considered transcription as a technical process that could be done by another person, but rapidly realised during data collection that the transcription process was integral to my ability to understand and analyse the data. The transcription process involved multiple re-viewing of each video which I started to think of as a *layering* process. The first layer was the initial watching and listening to the video. I watched each video several times and then transcribed the words. Transcription involved close attention to the video and it was during this process that I started to recognise the second layer which was the movements that each participant was making.

I identified the third layer when I watched each video with the sound turned off. It was only then that I realised that each participant was making not only the obvious larger body movements and hand gestures, but also very small body and facial movements that I termed “micro movements”.

These movements and micro movements were then transcribed alongside the words, and effectively demonstrated that there was another means of communication in use, that of embodied language. In order to stay true to each participant, during presentation of my analysis, I have included longer sections of narrative in a conscious effort to be respectful of the narrative whole and the person; the power of this data is in the whole and not in the fragmentation of the text.

### **5.14 Analysis**

Transferring large media files from a tablet to a hard drive can be problematic, so I consciously kept each video short by stopping and starting the video at natural breaks in the conversation. Videos were therefore between 15 minutes and 4 minutes in length. This meant that each participant’s data was composed of more than one video.

I watched each video multiple times, with the sound on, and with the sound off. At each watching and re-watching I asked myself “what is happening here” as each nuanced sound and movement occurred. Who is this person I am watching and listening to and what is important to them? I wanted also to juxtaposition this story with the biomedical one which had brought each participant into the hospital. It was equally important to remain cognisant to the fact that the data are a representation of one moment in time in one place, and that that there is no one stable and unitary interpretation.

Having initially transcribed the words of each video, I then focused on the movements and micro movements of each participant and transcribed these. Using an iterative approach to analysis, I collected the data in blocks in between which I started to analysis the data. I noticed the

movements that participants made in the first video, recognising that these movements did not always reflect the content of the verbal narrative.

As analysis continued, I recognised the layering of the narratives – words, movements and micro movements and started to look for sections of narrative that demonstrated what I was seeing. These representational sections were then used in the findings chapters.

However, the analysis was also framed through the lens of Hydén's (2018) narrative scaffolding. Scaffolding for people with dementia recognises that meaning making in conversation is a joint activity which requires collaboration. Hydén proposes three types of scaffolding: "activity frames" which considers the environment and general preconditions for the activity, wording and topic; "actions" which can increase the likelihood for constructing joint meaning; and "repair activity" which occurs when an acceptance of meaning is reached by either of the participants (p135).

Thus, during transcription and analysis, I looked for examples of scaffolding that were achieved through either words, movements or both. I therefore searched my data for sections of narrative that demonstrated the three types of scaffolding that Hydén has proposed, and used them to illustrate these points.

Stories can also become entangled in themselves, and the listener can equally become entangled by the disorganisation of the plot (Hydén 2018). To produce a narrative, especially an autobiographical one therefore necessitates collaboration between the person living with dementia and the listener (Hydén 2018) in order to disentangle the entangled. In this analysis the listener is also the watcher, and sections were selected that illustrated the way that bodily movements and words can contribute, or not, to collaboration.

The analysis focuses on narratives that are short, incomplete, or otherwise atypical - the "small stories" (Bamberg 2004) which do not focus on deficits and impairments but rather demonstrate talk-in-action, are jointly produced and dependent on the context of the local setting (Hyvärinen and Watanabe 2017). This talk in action captured the moment by moment narratives of each participant within the context of the AMU.

Thus an additional part of the analysis was to demonstrate a level of coherence between narrative types, a coherence that did not rely on the biomedical model for understanding. Again, the iterative approach to analysis proved useful, as at this time I was also reading widely. Frank's (1995) narrative typologies of Quest, Chaos and Restitution resonated loudly with what I was finding in my narratives, and were thus used as an additional lens through which the narratives were viewed, presented and understood. Sections of the narrative that illustrated Frank's typologies were therefore selected and discussed in the findings.

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The videos represent a short moment and space where we strive to understand and make sense of the other. However, the real issue in this context is around accessing and interpreting the meaning of what is being communicated. It is this issue of understanding and sense making of another's narrative that is the focus of the analysis.

It also became apparent to me that each narrative needed to be considered in its own rights. The power of the stories came from them individually and from within their individuality. I did not want to fragment the stories, look for common themes amongst the fragments and consider these together. This seemed too similar to the task orientated fragmentation of hospital care, and homogenous manner in which people with a diagnosis of dementia are often considered in healthcare (Ludwin and Capstick 2015). Therefore, within the findings sections I have presented larger sections of the narratives, and have not fragmented the text.

Additionally, I remained aware throughout the process of transcription and analysis that as there is no single interpretive truth, to make sense of data also requires the researcher to employ artistic and political practices (Denzin and Lincoln 2013) and to acknowledge that their interpretation is only one of many.

### **5.15 Data storage**

The hospital consent forms for photography and consent forms that were signed by proxies were stored in a manual file in a locked cabinet, in a locked office in accordance with the University of Southampton policy.

The video and audio recordings were downloaded onto the university J-drive for storage. No videos and audio recordings were stored at any time on the tablet; they were recorded directly onto a password protected SD card which was stored in a locked drawer separate to the tablet.

Where participants gave permission to use their videos in teaching or at conferences these were edited so that only sections of the recordings were used; no names were displayed and the video clips were transported on a password protected memory stick and then erased. No video clips were embedded into PowerPoint, or other, presentation software, but were manually loaded from the memory stick and deleted from the computer following the end of each session.

At all times pseudonyms have been used; however each participant is clearly seen in each video. The video has been shown and discussed with each participant or proxy and it is recorded which can be used for education and which are for data only.

Field notes were anonymised and typed up immediately after each data collection session and are held on a password protected laptop.

The data will be archived for ten years in line with University of Southampton policy.



## Chapter 6 First impressions

### 6.1 Overview

This chapter starts to address the first research question: *What narratives are shared by a person with moderate or severe dementia in social or medical crisis when they are an inpatient on an acute medical unit?*

The analysis has evolved over time and has been a process that I visualise as *layering*. This chapter illustrates the top layer: this is what I saw and heard.

The ethos behind the narratives that I have collected is that “narratives begin as living things created in the moment-to-moment action and interaction of particular people in a particular place, at a particular time, engaged in particular events” (Pinnegar 2007 p247). This is important to understand, as people living with dementia often live in the moment because memories of previous recent events can be difficult to recall. Therefore the “moment-to-moment” interaction gains heightened importance – “people will forget what you said, people will forget what you did, but people will never forget how you made them feel” (Maya Angelou).

The narratives that were shared existed only in the moment of telling, but in that moment information that was important to the person was conveyed. Here I consider parts of the first three videoed conversations that I collected.

### 6.2 Roger

As part of the recruitment strategy I had viewed Roger’s medical notes prior to meeting him, and struggled internally throughout our conversation to not let this interfere with how I heard his words. In his notes Roger had been labelled as aggressive, and during our time together it became clear that he felt that people were avoiding him. Roger chose to lie in bed and not sit in a chair. He was unshaven. He tried throughout our interaction to do up the poppers on his pyjama top. Eventually I offered to help and he told me there was no point as they didn’t work. We agreed that nothing seemed to work for him at the moment and laughed a little to relieve the sadness.

Roger’s frustration with his current situation was palpable and in my opinion completely understandable. His description of what was happening seemed apt “*it’s chaotic*”. However at other times he seemed resigned; at times he appeared hopeless “*there’s nothing I can do about it*”, and his choice of remaining passively on his back in bed reinforced this visually.

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Around us the ward moved; doctors came and went to the bed diagonally opposite as the patient was critically unwell. The background noise was loud and at times intrusive. Having introduced myself as a researcher, Roger remained unaware of my clinical background which made me feel slightly uneasy.

I did not realise at the time that Roger would be the only participant to speak overtly about his dementia and provide important insights into how this affected him. Roger spoke of how his diagnosis of Alzheimer's dementia changed the way that people behaved towards him:

R: My memory's a bit clouded because like I have got Alzheimer's disease [ .....] soon as they know you've got Alzheimer's disease a lot of doctors [say] oh well we know all about that and they don't; they don't know what they're talking about [.....] because it's only the person whose got it who knows what it's like.

*He gestures at me with his arthritic forefinger to emphasise points as we talk.*

R: One of the things about it, you see, I am perfectly lucid you know, I mean you listen to me talking

P: Perfectly lucid

R: Yes, yes exactly. But a doctor will come along he'll read on there umm suffering from Alzheimer's disease and he immediately assumes that you're a nutcase. Do you understand what I mean?

P: I do, I do understand exactly what you're saying

R: And it's not true and, and you can't, you can't get through to them. And I'm waiting now for a doctor to come and see me so that perhaps, maybe I might be able to go home today, but it is very unlikely.

Later in the conversation Roger use the phrase "*We can't release you today*" and I can see that he thinks of himself as a prisoner (of this place? Of his dementia?).

From his immobile position, Roger is hoping for movement. He recognises both through his words and his position on the bed that he has become powerless because of his diagnosis of dementia. Roger leaves an impression of suppressed anger. His jabbing right forefinger emphasises his words, he makes definite eye contact with me and uses both hands together to make gestures:

R: Its its there is nothing that I say that's not perfectly sane

*Looks up at me to his right; hands rest tensely on upper chest, briefly lift up together, looks away at end of bed; mouth downturned. Raises eyebrows, rolls head and looks at me*

P: No I completely agree, absolutely

*Adjusts his glasses with left hand; right hand rises from chest briefly and falls back; glances at me*

R: Well there you are. But, but, but they'll always but when they when they interview you

*Looks at end of bed; both hands lift; fingers of hands face each other, outstretched, tense and grasping; watches hands*

R: they'll always leave a little bit at the end meaning to say oh well yeah we can't really be sure he's alright

*Brow furrows; uses both hand to demonstrate "little bit at the end"; eyes flicker; turns head and eyes to me*

R: and there and there oh here we go again

*Rolls head back, closes eyes momentarily; looks towards end of bed, eyes narrowed; hands fall to chest*

P: How does that leave you feeling?

*Looks directly at me with wide eyes, lifts right hand to adjust glasses*

R: Pretty rotten... cos you know you're not going to get out

*Closes mouth; places hands tensely on chest; rolls eyes, looks to end of bed; tenses lips together*

Roger's narrative appears to be one of frustration and suppressed anger. Language is not just words, rather it is present in the multiple signs, mediated and created by the body through both conscious and unconscious movements; the mind does not simply reflect reality through a series of inputs and outputs, but actively creates it (Rosen 2017). The reality for Roger is that his sanity is in question and this affects his ability to make his own decisions about returning home; "you know you're not going to get out". It is not his dementia diagnosis that is problematic for Roger, it is the way that this diagnosis affects the way that other people treat him. His diagnosis has rendered him immobile on the AMU – he is not allowed to go home where he so clearly wishes to be.

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His supine position in bed with gesticulating hands seems to demonstrate the need to control his emotions; to not be seen as angry when such signs may well be interpreted as yet another symptom of his dementia.

Just as I am leaving, Roger insisted that I put a “footnote” (his word) after our conversation: *“Don’t get me wrong, some people are lovely. There are lovely people here”*.

### 6.3 Elizabeth

Elizabeth was beautifully dressed and sat in her chair which was on the access corridor which runs through the middle of the AMU. She had a chest infection and her voice was hoarse and slightly breathless. She was keen to talk to me and the conversation revolved (literally) around the time when she and her husband lived in France. The noise in the background at times threatened to overwhelm our conversation, but appeared, at first sight, not to concern Elizabeth.

When planning my videos I had decided not to ask direct questions about the AMU or the participant’s illness, but instead to start with an invitation to have a conversation with me. However, the planning went awry, as when I sat next to Elizabeth and set up the tablet for recording I immediately did what I had planned not to do, and made a direct request: “can you tell me what it’s like being here on the ward?” Elizabeth quickly brought the topic around to France:

E: Being here. Well, its, as things go, it goes very well I think. People you can talk to if you want to [coughs] but I spent a long time living in France anyway so I er, I er [cough] I haven’t had long conversations with the English people obviously I just speak in French, but ummm.....

P: What’s your French like now?

E: Not so good. But I don’t know that my English is all that good either.

Elizabeth very capably brought the topic of the conversation around to that of her choice. She talked of her time in France with apparent pleasure; the Elizabeth in France appeared to be the ideal; she was now far away from where she wanted to be:

E: Nowadays I don’t do very much because it worries my family if I wander, so, but they’re very good at taking me about when they can. I, I, I, just, I mean I like walking I just do wonder sometimes if I lose track I’ve got to get myself back [...] And that’s a bit worrying.

By focusing on France it appeared important to Elizabeth that I understood that she was not reliant on her family and still considered herself to be self-reliant:

E: I get taken to places, but its er otherwise but then I lived a long time in France on my own and so it was umm it doesn't bother me at all that I haven't got people; the French people were absolutely wonderful they always came to see me.

Whilst talking with Elizabeth I focused on her face and what she was saying which left me with the impression that she had been fairly cheerful, except at one point when she was remembering her husband. On first viewing the recording away from the hospital I had a similar impression but noticed that she was moving around in her chair. However as I looked deeper into the layers of narrative I recognised a different story.

Elizabeth appears to use her whole body to share her narrative. She moves back and forwards in her chair, rarely leaning against the chair back, and never relaxing. Her body movements appear tense and anxious much of the time. Her face and hands animate her conversation. Her face is mobile and expressive, clearly telling a story, periodically sad and then lighting up. My impression with the sound turned off is that it is hard work telling this story.

Elizabeth is telling me an autobiographical story that requires work from both her and from me, the listener. Hydén (2018 p49) called these "entangled stories" which involve both the teller and the listener in working to find a shared meaning. He recognises that this puts a heavy demand on both parties from which the only escape is to abandon the joint effort to understand, or to continue until a shared meaning is found. Hydén (2018) also recognises that a problem for people with dementia is to transform and translate internal memories into language, perhaps explaining Elizabeth's significant use of body and facial language. Memories are like an image, everything is there at the same time, but language is sequential and the whole needs to be analysed into smaller parts and ordered on a time scale. Elizabeth was achieving this in an unfamiliar environment with an unknown conversational partner and a level of background noise that was at times almost overwhelming. No wonder she was tired.

## 6.4 Rose

She looks so old; deeply lined face and furrowed brow; she doesn't use her left arm; so careful of her appearance, vestiges of lipstick. Background noise is loud, conversations, alarms. The noise suddenly stops. I try and take the cup as I think Rose is going to drop it; not the case; I mop up the dripping cup because I don't want Rose to get covered in tea stains.

At times Rose is sad, I'm sad. I am unable to support her in her story telling. Rose says each word slowly; she is clear that she is not from around here and does not know what brought her down here from Manchester. Her eyes are downcast then look up and hold my gaze, then looks down close to tears.

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R: I don't know how I come to be in [place] I really don't. I didn't come to see anybody.

P: you sound worried Rose. You sound very worried.

R: I am worried because I wonder why I'm down here

P: I think..

R: South of England

P: I don't know why you moved to [place]

R: pardon

P: I don't know why you moved to [place]

R: no, I don't know.... I've no idea why

P: have you enjoyed living in [place]?

R: (shakes head) no. I don't know whether I came to (swallows) change to see somebody or to change something. I don't think I did have any connections (shake head) with [place]. That's just

P: and before you were in [place]

R: can't think of anybody that I know in [place]. Definitely can't think of anybody I know

P: do you.....and before you lived in [place] where did you live?

R: Manchester

P: aaah, I thought I could detect a northern accent.....what do you remember about Manchester

R: yes I do remember Manchester very, very well [tearful].

Rose does not know why she is here. She is troubled by this strange and unfamiliar place. Her narrative is of being lost. Her tiny body is wrapped in a blanket and I wonder how we can possibly be trying to help her in this environment. Everything is done by Rose slowly and deliberately, even eye movements and mouth; it is as if Rose is moving in a dream. It is hard for me to slow down to her speed.

I felt wrong to be videoing Rose, she was the first person who I really don't think understood what I was doing, and I felt uncomfortable, even though Rose was happy to have a conversation with me, and her son as proxy had also agreed. He told me that he was happy for me to make the video but to use it only for research and not for education or more public display.

## 6.5 Context of the AMU

Data collection also included observing the AMU, watching interactions between patients and healthcare professionals and observing patients in order to capture the context within which the narratives were shared.

*AMU 2. Lady sat in chair, watching cleaner; cleaner does not acknowledge the lady as she dusts under her bed, crouches on the floor right by her feet. The lady sits watching as 5 people intermittently pass by. Cleaner continues. 8 people at nurse's station, phone rings. Occasionally moves her head. Bed beside her lady is asleep. Then gets interested in something to the right, turns. I can't see what she is looking at. Rubs her hands anxiously, then puts forehead in hands. Bows her head, hands clasped in lap. Is she falling asleep? Withdrawing? Cleaner back again, mopping the floor around her feet, still doesn't acknowledge the lady in the chair.*

*Alert again watching ahead – suddenly 8 people in front: 3 around computer, 1 cleaner, 2 at notes trolley, 2 nurses passing. Hands rubbing each other in lap, turns head to right where cleaner now cleaning under that bed. Still watching what is going on. Leans backwards, hands in lap; turning head to watch. So many people, but no one has interacted with her in 10 minutes. Another 5 people in front, 3 passing by, 2 at notes trolley, cleaner back.*

This lady was invisible and her *dignity of identity* (Nordenfelt 2004) had been lost within the hypermobility of the ward around her. Dignity of identity is the dignity that we attach to ourselves as integrated and autonomous persons, persons with a history and persons with a future with all our relationships to other human beings. This dignity is vulnerable and can be taken from us by external events, by other people or by age or illness (Nordenfelt 2004); or in this lady's case a combination of all four which had effectively made her invisible. I later spoke to this lady:

*All of them without fail are nice which is lucky for me. I don't I don't try and rock the boat anywhere so that's so that's .....you're what you want to go you want it it's the best thing to do. Aren't they after all or not. So I just go and come when I'm told. They they haven't got they can't say oh you're this that and the other because I do exactly what they want. oh its been learnt for years I mean if you're in hospital they're so busy if you start messing about then this that and the other they haven't got the time.*

She clearly understood that keeping her head down and not rocking the boat was the best strategy in a busy place; she maintained her dignity by doing what she was told. However, my earlier observations of her body movements in the chair whilst being ignored by all around her, including one person at her feet, indicated a lady who was uncomfortable and anxious in this position of invisibility.

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The dignity of identity that can be conveyed by storytelling was evident in Elizabeth's narrative. Elizabeth recalled her time in France with her husband, her ability to converse in French, and in later conversation her love of singing and music. She may be a patient on an AMU but her words made her identity clear. Yet this dignity had to be maintained against a backdrop of noise and constant movement of people and things. Elizabeth showed by the movements of her body in the chair what an effort this was to achieve.

Contextual information was collected as field notes of observations of the AMU on days when recordings were made. On one typical occasion I stood quietly at the centrally placed nurse's station in the middle of AMU3 and observed:

*Bed 15. Thin ashen lady, fragile looking; lying in bed; 2 relatives in attendance standing over her. Looks uncomfortable. Noisy, alarms x 2, IV lines. Call bell alarming in background. Blood transfusion running, BP cuff on arm. She looks uncomfortable; legs half out of bed. No teeth. The nasal specs keep slipping off her nose. Relative holding her hand, stroking her head. Gasping for breath. Critically unwell. Seen multiple times through the night. 13 people at the nurses station overlooking bed 15. She looks uncomfortable. Eyes open, staring. "On AMU 3 dealing with a sickie" says doctor on phone.*

*What am I looking at? Chaotic, noisy. I wonder if this lady is dying.*

The videos capture the cacophony of noise that is the background to daily life (and death) on an AMU where some struggle to hold onto the threads of life. Soundscapes were recorded on busy days:

*Talking; snatches of conversation; so many people talking; sounds as if I am in a crowd; man shouting "leave me alone, leave me alone"; voices louder, rising in density; filling my head; snatches half heard; banging door; coughing; alarms beeping, beeping, beeping; voices; chair scrapes; object banged on table; snatched words; cupboard slams; voices, voices, voices.....*

The silence at my desk is a relief when the soundscape is turned off.

There are multiple transient, unpredictable and often irritating sources of noise in an AMU. The sound of beeping alarms is ever present due to the acute nature of the medical issues being addressed. These are recognised as having a negative effect on the hospital soundscapes, yet their clinical validity is questionable with only 15% of alarms are actually responded to (Shield et al 2016).

The World Health Organisation (Berglund et al 1999) guidance on noise states that the critical effects of noise are on sleep disturbance, annoyance and the communication interface, including

interference with warning signals. There is growing evidence that poor hospital soundscapes negatively impact both patients and staff, resulting in hindered recovery and increased communication errors (Bliefnick et al 2019). Noise in itself can become disabling when it means that someone becomes exhausted due to lack of sleep, and is unable to hear others, or hear themselves speak. Yet, a survey of noise levels and identification of noise sources in 31 locations in 5 general inpatient wards in 2 hospitals has shown that patient accommodation is subject to high levels of noise which is greatly in excess of WHO guidelines (Sheild et al 2016).

It was not always hectic on the AMU. I arrived late one Saturday morning in late December and found the unit unexpectedly quiet. There were a significant number of empty beds. The staff were all warm and welcoming. A man was highlighted to me by a nurse who asked him and his daughter if they wanted to hear about the study. The daughter said they would but she was concerned that I would use long words – her father did not attend school much. When I went over to speak to him he was coughing and complaining of a headache. He was just not well, so we passed the time of day and I thanked them and left.

## 6.6 Summary

When people with dementia are admitted to hospital in medical or social crisis they have narratives to share. Roger, Elizabeth and Rose challenge the homogenous diagnostic labelling of “dementia” by revealing three different people with very different narratives. Their narratives show capable story tellers who are able to impart what is important to them in “the moment-to-moment action and interaction of particular people in a particular place” (Clandinin 2007 p247). Albeit not in the form of biomedical narratives that might be expected from an interaction on a hospital ward.

Each of the narratives discussed here, can be considered to provide some insight into the participants personhood - of who they are and what they are experiencing in the moment of the telling. Roger tells a story of frustration and how other peoples’ responses to his dementia serve to negate his sense of sanity; Elizabeth’s story moves in time and space and shows the work needed to share a narrative that describes her as she wishes to be seen; and Rose’s story is of being lost.

If time is made to consider these narratives; the ones we tell in passing, in our everyday encounters with each other (Bamberg 2004) then an initial step can be taken towards understanding and upholding another’s personhood. Without attention to these stories a sense of personhood can get lost, as a lifetime of experience, knowledge, and skill can be replaced by a

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diagnosis that pathologises the person and reduces him or her to the homogenizing label of “dementia” (Ludwin and Capstick 2015).

The stories were told against a backdrop of noise, people and movement, and reveal that sharing these narratives involved work from the participants as well as labour from the listener (Hydén 2018). It was hard work to listen unconditionally, to disentangle the narrative structure, limit questions and assist in sense making, without taking over the storyline (Hydén 2018); and to slow down to the narrative pace of the teller.

This initial narrative layer alerted me to the importance of the movements and micro movements that the participants were making both consciously and unconsciously. Chapter seven looks for underlying layers of meaning within each individual story, specifically by attending to these movements, and I attempt to enter imaginatively into the worlds that are being *portrayed* to me; to look through the surface of the stories and see the depth that lies beneath.

## Chapter 7 Personhood through the lens of mobility

### 7.1 Introduction

Throughout the analysis of data I have attempted to follow Bresler's (2006) suggestion that narrative enquiry is grounded in auditory, kinaesthetic, and aesthetic sensitivities; and that these aspects infuse the processes of interviewing, analysis, and writing. Bresler also notes that just as they function in art and music, these aspects of perception and engagement in a research context involve interplay between part and whole, description and interpretation, tightening one's focus and widening it.

This chapter addresses the second research question: *Does a mobilities lens help in the understanding and interpretation of the narratives?* The chapter builds on the preceding one and continues to address the first research question: *What narratives are told by a person with moderate or severe dementia in social or medical crisis when they are an inpatient on an acute medical unit?*

Having watched all the videos with the sound on, I then re-watched them with the sound turned off. I started to recognise that there are stories being told beyond the words, that there is a performative, bodily element to the narratives and that these bodily aspects were the visual manifestations of personhood as a mobile process.

In research literature, although the body is seldom explicitly denied, its presence has an ethereal quality, forever gliding out of analytic view (Kelly and Field 1996). This narrative analysis aims to pay attention to the ethereal, by making visible the language of embodiment; and through this start to position the mobile body as central to the social process (Kelly and Field 1996).

For a person with dementia, the body is a substantive means of engaging with the world and fundamental aspects of personhood can be manifested in the way the body moves and acts (Kontos 2005). This analysis therefore pays close attention to embodied language as it relates to both the narrative and to each participant's expressions of self – their embodied personhood. When embodied language is considered, the body can express a sense of self because it is an active, communicative agent that contains its own knowledge, intention and purpose (Kontos 2005). The practical aspects of how this form of embodied language can be seen and understood are considered below.

The analysis uses a performative approach as suggested by Bresler (2006), which in many ways is more complex than just analysing the narrative as a text, but at the same time makes it possible

to discover and see new aspects of human social interaction (Hydén 2008). The transcriptions therefore contain movements and micro movements, and are not considered solely as closed, realist and empirical reflections of what was spoken (Chadwick 2017).

The analysis is explorative, and takes place at the micro level whilst also taking into consideration the macro movement of the surrounding AMU. It is based upon several sources of data, including moving images, audio recordings, transcribed text and field notes. However data analysis is a subjective process of construction and interpretation, data in themselves cannot be valid or invalid; what is at issue are the inferences drawn from them (Hammersley and Atkinson 2007). What follows is my interpretations of what I saw and heard.

## 7.2 Movement

### 7.2.1 Jane

Jane's is a story of chaotic movement. In Frank's (1995) narrative typologies the chaos narrative imagines life never getting better and stories are chaotic in their absence of narrative order (Frank 1995).

Jane has been admitted to the AMU because she had fallen over, and as she had been unable to get up, had remained on the floor until her carer arrived later in the day. She had sustained a fracture of her left hand, but is otherwise medically well. Discussions are being had amongst the healthcare team as to whether Jane should be discharged home or to a rehabilitation hospital. Jane wishes to go home. Jane has bipolar disorder as well as a diagnosis of dementia. She was lying in bed but I suggested she sat in a chair with her cardigan on, which she agreed to, returning to bed after our conversation. Behind me was the nurses' station and people walked behind me constantly.

Jane consented to make the video and was happy to keep it after we had reviewed it together. She told me that she does not want the video on "Coronation Street"<sup>4</sup> which I take to mean wider audience, but she is happy for me to use the video for my data. She videos me, videos herself but touches the pause button so we only get a snippet.

We review the video together and Jane comments on her frequent laughs "I just think it's me illness; part of me illness". At one point when she says that I look old she comments "that's rude of me, I shouldn't be rude". On further viewing she says "you should show people, I don't look

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<sup>4</sup> Coronation Street is a popular soap opera based in England

too bad” but I am not comfortable with showing the video to others, as I do not think that this comment means that Jane is allowing me to show the video; and I keep it only for data.

Jane constantly readjusts her position, makes big back and forwards movements, leans in towards me, rocks sideways and makes expansive gestures to people passing by. Jane seems like the embodiment of the hypermobile environment. She talks in fast staccato sentences and punctuates her speech with sharp, quick bursts of laughter.

Jane starts the conversation with no prompting from me:

J: Yeah yeah. You get fed up you know especially new places I think people like me make you go funny don't they?

*Looks directly at me, chin raised, mouth downturned, brow slightly furrowed. Screws up eyes, mouth square shaped, leans towards me with forced laugh lasting seconds. Stops instantly, leans back, mouth downturned, eyes relaxed, chin up, looking behind me*

P: In what way?

J: It's not my fault I've never had children I've never been married did you know that yeah

*Quick shake of head, lips pursed, brow furrowed, looking at me, raises chin and eyebrows; eyes wide, mouth downturned*

P: I didn't know that about you

J: You do now are we talking already

*Face relaxed, small nod, looks down at tablet, back up at me, rapid explosive laugh, stops instantly and looks to left*

P: We are. Talking already

J: Everybody keeps thinking they put me down as Mrs and I think I'm supposed to pay for

*Looks at me, looks to right, eyes slightly furrowed, mouth relaxed. Looks at me, turns head to left, moves head centre, eyes still left.*

J: The care that I have cos they charge me for it they think that I'm

*Small jerk of head to look at me, mouth downturned; moves head and eyes constantly from side to side as follows movement of people behind me, brow furrowed, mouth tight*

J: Hello

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*Sudden exaggerated eyes and mouth wide, hand raised in greeting as someone passes behind me*

J: [mouths] my friend

*Instantly drops hand, face relaxes, still looking behind me, rapidly indicates to right with sweep of hand. Shoulders raise, short forced laugh*

J: She's a nice lady

*Looking up and to right with teeth clenched smile, narrowed eyes; brief upward movement of right hand, throws chin in air, mouth wide, short sharp exhaled laugh*

J: We're gonna get oh no its us that's getting married isn't it

*Chin down, looks at me, rapid tiny shakes of head, brows furrow, mouth downturned; screws up eyes rapid forced laugh*

The word I want to use when watching Jane is “manic”. At no point is she physically still, and her words feel physically mobile, leaping in topic and place. This fragment of conversation and its accompanying movements took only 43 seconds, included approximately 44 movements and micro movements and changed topic seven times. I was unable to verbally scaffold (Hydén 2018) Jane's conversation as it leapt from topic to topic. However, I was able to understand the impact that the AMU was having on Jane.

The chaos of the AMU appears to have become embodied in Jane's movements and words. Jane was constantly distracted by movements of people and equipment, and our conversation was dominated by background noise. Jane needed an activity frame (Hydén 2018) that could scaffold her, somewhere quiet with people who had time to converse with her – to “build relationships, connect with me” (Bridges et al 2019). Recognition of this story of Jane's verbal and physical hypermobility can start to explain why people become adversely affected by an admission to an acute hospital. If people cannot stop moving, exhaustion must soon follow. Yet Jane is not physically moving from her chair beside her bed, and the intensity of her movements in the chair are not recognised as a form of communication by the staff around her.

Attention to Jane's movements in the chair reveal that she responds physically to each person that moves into and out of her field of vision, and to the noise and movement that surround her. This constant distraction may have been the reason that her topics shifted so rapidly and frequently. Yet it is within this environment, with no scaffolding and an unhelpful activity frame, that Jane is being assessed for her fitness to return home.

The body has a “generative, creative capacity to understand” and to express (Kontos 2005 p562). Kontos termed this embodied selfhood which she envisaged as being the embodiment of culturally specific conditions of socialisation which inform the way that people move and respond. Jane is the embodiment of the hypermobility of the AMU, and perhaps an embodiment of her bipolar disorder; she is literally never still.

Within this environment Jane had been assessed using standardised cognitive tests, “those dementia tests” as Jane told me off camera. The resulting decisions around whether she could be discharged home or not were based on these tests, despite research evidence showing that noise can detrimentally effect the outcome of cognitive tests in older adults (Dupuis et al 2016). Jane had been assessed to not have the capacity to make the decision to go home; she was awaiting discharge to a rehabilitation bed.

### 7.2.2 David

David’s is a chaos narrative (Frank 1995). There are no words in this story, just an embodiment of misunderstandings, distress and chaos. A person who is truly inside a chaos narrative cannot verbalise this because the construction of a story requires the teller to look back at what has happened from beyond the chaos, and this entails a reflexive understanding. If this understanding is present, then the person is no longer in chaos. As Frank asserts “those who are truly *living* the chaos cannot tell in words”; these stories can only be lived (p 98). Thus to understand a chaos story is to understand the movements of the teller. However, although Frank argues that the body is the vehicle of the narrative, he does not take the consideration of embodied language further. Kontos (2005) talks of embodied language but gives few examples. David shows in a practical way how communication can be embodied in movement.

David, whose story I recorded as field notes and observations, was inside a chaos narrative. David has Lewy Body dementia the symptoms of which includes visual hallucinations. David was trying to stand up from his bed and move off, but was being prevented from doing so by a group of staff who were attempting to make him sit down. During the course of this interaction David did not use words.

*I headed over to the commotion. There were now six of us and David was really upset. Grasping at the curtain, pulling, face tight. With his free hand he hit out in front of him, flailing; I went up in front, put my arm round his shoulders and squeezed him gently; “be careful he hits” said one of the nurses. I stroked his head, told him it would be alright. He looked at me, at my eyes; I asked everyone except two people to go, and for them to be slightly behind and out of David’s line of sight. He really looked as if he would fall so I asked for a chair behind him. I stroked his arm and*

*shoulders; “it’s frightening here isn’t it; you look so frightened; it’s alright David, it’s alright”. Gradually his hand relaxed from the curtain and took mine, his face looked less tense; one healthcare assistant took one hand and I kept holding the other and we walked a few steps; David was looking at my face and raised my hand to his mouth and kissed it. Then he sat in the chair behind him; I knelt down to maintain eye contact. He tried to kiss my face and I didn’t know how to react so he got me firmly by the throat and back of my head and pulled me towards him. It did not feel aggressive, but I couldn’t interpret what he wanted, I felt vulnerable and exposed. I pulled away slightly and he got upset again, tensing his face and maintaining a firm grip on my neck. There were now six people again, pulling at his hands. I managed to duck my head down and out of his grasp and could look him in the eye and speak and calm him. I asked all but one person to leave us, and again I stroked his arm, kept saying “it’s alright, David, it’s alright”. He relaxed against the back of the chair, watching me.*

This story sums up so much of the difficulty of understanding where a person is in their own story in an acute medical unit. Even as I write this I can feel my heart rate increasing and I know that I am holding my breath. I believe that he mistook me for his wife, and that was why he wanted to kiss me. In the moment it was all so different. My own narrative was at times forefronted. Initially I knew that I could calm and reassure David, but equally my concern was that I had become involved in a situation in which I was putting myself forward as an expert, but was I? Would I let him fall over? Would I let him hurt the adjacent patients? When David tried to kiss me, I became acutely aware that I was the centre of a great deal of attention from staff, surrounding patients and relatives, as by this stage we were right in the middle of the unit. Actually, it would not have mattered if he had kissed me, but my exposed position did not allow me to put David in the front of my thoughts and actions; at that time I could not attend to his narrative, only to mine.

On reflection, I believe that David was terrified, disorientated and hallucinating. Although his story is of chaos, within it David was on a quest for security, food and fluid. After this exchange I offered him a sandwich and cup of tea; he ate and drank quickly appearing to be hungry and thirsty.

The chaos narrative is probably the most embodied form of story, yet Frank implies that chaos is held at bay by a processing of words (Frank 1995). In David’s case he either could not speak or did not wish to; he could not tell of how his current situation was affecting him, because he was inside his body. His body became the instrument of the telling, his “body voice” through which his chaos story could be processed.

To deny a chaos story is to deny the person telling the story, and people who are thus denied cannot be cared for. The chaotic body is often victim to dominating bodies, which make it the

object of their force; and although people can receive treatment and care, they cannot participate in an empathic relationship (Frank 1995). The worst thing that medical staff can do to someone in a chaos story is to rush them, which negates what is being experienced and increases the chaos.

In fact, all the individuals present in this narrative were physically present with each other and could thus use their bodies as communicative resources (Hydén 2018). This body voice that could speak of what was happening needed interpreting, yet in the chaos of the moment interpretation was not possible for either the healthcare professionals, or for David.

Although embodied language, often in the form of hand gestures, is used in everyday storytelling such as when we describe the size and shape of an object, David's embodied language enacted his emotions in the moment without conscious intent. This embodied language is difficult to interpret from the outside because our desire to recourse to spoken language is so strong that it takes an effort to resist (Killick and Allan 2001). Within healthcare this embodied language tends to be seen by healthcare staff as the personal malfunction of the patient (Frank 1995), and not considered as language at all. Chaos stories cause anxiety because they represent the triumph of the illness over the treatment; they represent a failing of our healthcare, and show how easily it could be us in this story (Frank 1995). They are frightening. The anxiety that these stories cause prevents us from listening to them, and David clearly demonstrates this here.

The biomedical narrative considered that the way David was behaving was due to his individual attribute of having a dementia diagnosis, and not to the care practices that did not allow for a more nuanced understanding of communication strategies. Reframing a diagnosis as a social rather than an individual problem then requires everyone to do and behave differently and to address wider societal issues (Frank 1995).

Frank recognised the negative effect that healthcare staff can have on someone in a chaos story when they attempt to rush them to move on, or divert them back to the professional's direction. This is exactly what we were trying to do in David's case. We all (myself included) wanted to get David back to his bed space, to be sitting in a chair, and restore order; there was no dialogue between the healthcare staff that went beyond the gaining control of this narrative and getting David to do what we wanted. We interrupted David's narrative because it was too painful to hear. David was not being seen for who he was: a frightened, hungry, thirsty man in need of reassurance.

### 7.2.3 Brenda

Brenda's story is a story of embodied despair. Brenda was on the AMU due to a suspected urinary tract infection. Her bed was opposite the nurses' station which was busy with people, conversations, phone calls and movement. Brenda had been attempting to get up and move around, or perhaps even leave the AMU. Brenda had been assessed as a "falls risk" and as such had been allocated an individual healthcare assistant (HCA) to be with her at all times. This is termed as being "specialled". I walked over to Brenda's designated healthcare assistant, Sophie, and asked her how Brenda was. "She keeps running away" I was told.

*I went over to an agency HCA who was specialling a lady with dementia. Brenda was lying on her bed, bed rails up on one side; turned on her side away from Sophie. Sophie sat reading Brenda's magazine. Sophie's voice was loud and authoritative "she keeps running away so we're keeping her in bed". I said that I didn't think that was acceptable, if Brenda wanted to get up she should. "No she has to stay in bed because she refuses to wear her red socks; she took them off. She insists on those blues socks. I can't allow her to walk around in her socks". Brenda was wearing a hospital gown and her legs and pants (with pads) were showing. I found a blanket and covered her legs. She didn't want to get up and pointed at me and Sophie in an accusing way "and you" "and you" she said, but did not make eye contact. I found her bag and her slipper boots and the note book inside which described exactly what her carers did for her, and her clothes and a bright pink, handmade apron that she wore at meal times. Sophie was uninterested.*

Brenda illustrates the culture of restriction and restraint that prevails when a person with dementia attempts to move around whilst an inpatient (Featherstone et al 2018). Her attempts to walk around the unit have been interpreted as "running away"; a symptom of her dementia rather than a normal desire to move away from a populous and noisy area, or perhaps find a toilet or comfort. Incontinence pads were utilised instead of frequent trips to the toilet. Brenda was not able to tell staff of her likes such as her blue socks, her dislikes or her routines, so her carer had written it all down in the notebook, which had not been read or acknowledged.

It is no surprise that Brenda pointed an accusing finger at me and the HCA "and you" "and you", but made no eye contact. Brenda is being cared for as a task – "a fall to be avoided" – and not as a person in need of compassion, understanding and company. Brenda has no freedom to move, no choice and no one is listening to her voice. Her curled up position in bed spoke to me of despair; her pointing finger delegated responsibility. There is a truth in these movements that if acknowledged, cannot be denied.

#### 7.2.4 Arthur

Arthur's story is of a quest to make sense of his surroundings. Arthur was the only participant who walked around whilst we conversed. This conversation with Arthur took place in a quiet side room, with no external windows, where he was recovering from flu. The room was near to the main entrance of the unit, and he stopped periodically from both his bed making and his conversation, to watch the people that he saw pass by the window.

Arthur was clear that he did not want to be videoed and so this was an audio recording. Whilst capturing the "fleshiness" of his words in the form of tone, cadence and emotion behind the words (Chadwick 2017), the recording did not enable the capturing of his micro movements as he straightened the sheet on his bed. His methodical movements, up and down each side of the bed as he moved carefully back and forwards along one side pulling at the sheet; stopping to look directly at me with his piercing blue eyes, could only be captured retrospectively as field notes. The finer details of his facial expressions and micro movements could not be reviewed and considered.

However, although Arthur's micro movements were not captured his larger body movements portrayed his personhood through his embodied language. Arthur moved back and forth along the sides of his hospital bed, twitching and smoothing the sheet, until the sheet was worthy of that on a naval man's bunk. These embodied actions of his naval self were confident and adept, in sharp contrast to his fragmented words as he tries to answer my question "were you in the navy in the war?"

*A: Yeah. Well I was and I wasn't. I was on the HMS yeah I was I forget what I was then um I was in the Navy what I was now will come back to you later on. But um its quite interesting actually, but um, yeah. Well, I wouldn't mind, I wouldn't mind going back. Of course its not the same now is it?*

P: I think it would be very different now, going back, yeah I do

*A: People um don't seem to understand what people like in those days. But um*

P: in what way do we not understand?

*A: Well um. I don't know you get the impressions with the higher ups and the lower um bodies people down coming up through the ranks to major, some of them very good and some of them very awful you know*

P: hmm, hmm

*A: But um yeah its all quite interesting I suppose*

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P: it sounds really interesting

A: *Yeah. Um.*

P: am I in your way because I can see you're making your bed

A: *Well yeah its, its, ddd, its err its as it stands I think. [sees people through the window] Yes, yeah. Packing up now. You packing up?*

P: no, no, I don't think they're packing up now, no. they're just people out there doing their jobs.

A: *Yeah. So um I suppose what you see about you know um course there was none of these name my day*

P: what did they have in your day?

A: *Well they didn't have any these like this did they?*

P: I guess not, no. they are pretty high spec high tech now.

There is little in Arthur's immediate environment that can assist him in sense making. He is in a clinical side room containing an electric hospital bed, a chair and a side table. There is no outside window. By referring back to his previous experiences in the navy, Arthur actively attempts to make sense of where he is and to understand his place within it, which involves both existential and social dimensions (Örülv 2010).

Arthur recognises that his life in the navy was in the past, that he wouldn't mind going back but realises that things would have changed and people were different then. Through the window he can see people going about their business and he asks "*Packing up now. You packing up?*" and I believe that for him these people were in the navy. The one object that does seem to make sense to Arthur is the bed, although this is modern and Arthur comments: "*Well they didn't have any these like this did they?*" It is around the bed that Arthur spends his time perhaps using this as a solid connection to a world that he could understand.

As Arthur is in a side room he has not had the opportunity for social connection with people, except for when health professionals perform tasks, and during this conversation with me. His quest to make sense of where he is, has been a solo venture, and perhaps this explains his attention to his bed making. The work of becoming a patient for Arthur was in retaining his identity in a new and difficult environment.

## 7.3 Micro movement

### 7.3.1 Elizabeth

Elizabeth's story appeared first as a restitution narrative (Frank 1995) where she restores her former self to the listener and maintains her dignity of identity (Nordenfelt 2004) through the words that she used. However, attention to her movements and micro movements show how much work she has to do, in order to collaborate in a conversation.

Elizabeth sits beside her bed and is neatly dressed. She is a bit hoarse and has a chest infection. She is quite breathless as she speaks. She has a cannula in her right hand and is holding the newspaper on her lap. There are conversations, coughing, mobile phones, banging and clattering of trolley wheels intrusively in the background, at times almost drowning out her words. When re-listening, the background noise is exhausting.

In Elizabeth's story she is following a line that suddenly digresses and then returns later to the storyline (Hydén 2018). This in itself can be quite joyous as Elizabeth skips back and forth in time and I follow her from here on the ward to France, through courting, marriage, childhood and grandchildren; the leaps in space and time interspersed with returns to her life in France. Loops of her life which she generously shares with me; I visualise the story like the flight of swifts when they arrive over my house in spring, swooping, spiralling, sweeping across space, disappearing and returning.

That was the effect of Elizabeth's words on me; but close attention to her body movements suggests a different story. As the noise around us gets louder, as I watch the video again, it feels as if Elizabeth's eye contact is becoming desperate; it feels as if she is having to cling on to me to tell her story. I wonder if this is another form of scaffolding.

E: He wasn't a husband he was a friend

*Forwards in chair looking at me; draws brows together; head slight tilt left; eyes narrowed, rapid blinking; smiles; small back and forwards movements in chair*

P: that's a lovely thing to say

*Eyebrows rise briefly; quick jerk of head left; looks back at me; smiling*

E: Thank you. We um we loved each other, we never did anything alone or very very rarely

*Looks left and up, brows furrowed; turns head to me, nods, eyes stay on me, turns head slightly left; eyebrows raised.*

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E: He sometimes he went to um work and not whilst we were in France

*Blinks hard several times; looks at me; shakes head rapidly; looks left; shakes head, looks at me*

E: We were um we were retired and very happy

*Leans back in chair, looking at me, lifts chin, smiles, head tilts right; nods head, looks up and left*

E: And walk we could walk down

*Looks at me; large downward sweep of left hand; raises left hand up*

E: And the people in the village after my husband died the people in the village, the people in the village

*Drops hand to lap; leans forwards; looks down and left; brows furrowed; leans further forward; looks at floor*

E: I know people are rude about the French sometimes

*Looks up at me from corner of eyes; brow furrowed; rapid shakes of head; eyes screwed up*

E: But they I, I walked down all the way from my house and um I'd do my shopping or all the things I wanted to do

*Deep breath in; looks back at me; indicates walking down left hand; brief glance down to floor; back at me; eyebrows raised; hand in lap; looks at me eyes wide; moves back and forwards in chair; looks at floor; brows furrowed; looks at me, head tilted left; eyes wide; rapid sideways movements left hand; looks to left; moves back in chair; looks back at me; gestures with left hand*

E: And then they'd say "Just knock on the door we'll drive you back" always, there was always somebody that would drive me home so I was never that worried

*Eyes wide, small nods, smiles; downward sweep of left hand with "knock on door"; chin tilts up; indicates over left shoulder with left hand; glance down and left, back at me, eyes wide; slight shake of head; slight narrowing of eyes, moves forwards in chair; smiles at me, head tilted left*

Elizabeth uses her body position in the chair, hands, face and eyes as she tells of her husband and her life in France. She has chosen the topic and at times uses hand gestures to support her words; but it is the other micro movements that when attended to indicate the state of tension that Elizabeth is in. She is never still; her head turns frequently to the left where people pass by; her eyes look at me, away, down, left and back again to me; her body moves in the chair. Her body and eye movements are rapid and intense and increase in frequency when she talks of her

shopping trips in France. Telling this story against a hypermobile and noisy backdrop is clearly effortful.

We continued our conversation:

P: That is nice. What made you leave France?

*Nods, eyes narrowed, glances left, looks back at me, small smile*

E: I came home for Christmas and I couldn't ask my family

*Looks at me, eyes wide, deep breath, stops smiling; glances left, leans back and left; forwards, back; looks at me; shakes head, eyes wide, eyebrows together, mouth downturned*

E: I was beginning to get um well disorganised if you like and I er I couldn't worry them

*Moves back in chair; leans left; eyes narrow; looks at me; glances left, back at me, slight nod, eyes narrow; moves forwards, slight nod of head, eyes widen; moves back then forwards; shakes head with eyes wide, brows drawn together, looking at me*

E: I certainly couldn't expect them to dive out of England to every so I so that's why I came back here

*Lifts chin high briefly, moves back, eyes narrowed; glances left, back at me; sharp gesture with left hand to illustrate "dive out"; moves forwards, brows furrowed; looks down and left, rapidly nodding*

E: But I miss France greatly

*Leans back in the chair looks at me; small nods; smiles*

And as I pay closer attention to Elizabeth's words and movements I start to understand that this is a story of loss; loss of a husband, loss of her home in France and the loss of independence. Her micro movements, disturbed and disrupted by the noise around us, show a downturned mouth, narrowed eyes, furrowed brows and only a fleeting smile; the movements increasing in frequency as she considers becoming "disorganised". The internal sadness of Elizabeth's world is displayed, but acknowledgement of this requires close attention to her and her situation. Elizabeth is working hard to convey her inner world, and I start to recognise the work that is required to hold on to a sense of self in a loud and chaotic place: this *work maintaining personhood* is a mobile process, and it looks exhausting.

### 7.3.2 Rose

Rose's movements are small and slow. Rose's story is a micro quest for her cup of tea. The quest narrative (Frank 1995) gives the ill person a voice as the teller of her own story, as opposed to the chaos narrative where the suffering is too great for the story to be told. The quest narrative speaks from the person's perspective and holds chaos at bay. In Frank's category, quests are a reflexive attempt to gain something from the experience of being ill, and gives the ill person a voice as teller of their own story. In Rose's micro quest words are secondary to the intention of her body.

Rose's dementia is quite severe which will have affected her cognitive functions such as planning, remembering and language skills. She is in a new and noisy environment and in the last two days has transitioned from her care home to the ambulance, to ED and then to the medical unit where she is now. The ward soundscape is of voices, footsteps, equipment clattering, and a phone ringing. People constantly walk past directly in Rose's line of sight. What Rose hears and sees is movement. Sitting beside her bed wrapped in a blanket Rose is not a part of this movement, she sits apart both physically and metaphorically. Rose's movements and words are slow and contrast sharply with the mobility that is all around her - we have our normative language and conventions around body and interactions, but Rose's world is different now.

I had made Rose a cup of tea and had put it on her table:

- 1 R: *Looks down to right and moves a piece of paper to reveal the roll of tissue*
- 2 P: tell me about Manchester
- 3 R: *I can only move very slowly*
- 4 R: *Keeps head and eyes down as she says this*
- 5 P: that must be very frustrating
- 6 R: *swallows twice; is holding the roll of tissue with right hand and focusing on it; moves left shoulder to try to tear off a sheet but arm does not follow. Looks down at the roll and then away into the distance behind me, still holding roll in her right hand but looking away*
- 7 P: I can see what she is trying to do with one hand and I take the roll
- 8 R: *sees me tearing off tissue.*
- 9 R: *I want some paper to blow me nose*

- 10 P: there you go
- 11 R: *Moves her gaze from downwards to the right, rocks her head twice then looks briefly at me. Blows her nose very carefully using only her right hand, she looks into the middle distance with huge eyes and tiny pupils; slowly puts the tissue down, rests her head on her right hand and rubs her forehead looking down. Raises her head, sniffs and looks directly at me*
- 12 P: Hello?
- 13 R: *Holds my gaze for a moment; puts her head back on her hand and rubs her forehead looking down*
- 14 P: I got you your tea Rose
- 15 R: *Continues rubbing forehead; stops, looks down to the left and right*
- 16 R: *thank you*
- 17 R: *Stops rubbing her forehead; looks down towards the tea mug with head resting on fingers of hand and to the right then briefly in front and up to right then rests cheek on back of right hand*
- 18 R: *is that tea?*
- 19 R: *Looks directly at me briefly then back to the mug and reaches out with her right hand*
- 20 P: it is
- 21 R: *Picks up the mug and starts to drink. Looks down at the mug and takes 4 gulps of tea; I mop up a drip and her eyes look down towards her blanket; takes another gulp, she acts as if she is going to put the cup down, I go to take it; she is not and keeps hold of it her eyes watching the mug; takes 4 more gulps whilst looks to the right and back to the mug; I mop another drip; looks down at my hand then at the blanket; glances at me then to right and left quickly*

In order to understand this exchange, Rose's embodied language must be understood. First observations suggest that Rose is not engaging in this conversation, but if the listener/observer slows down to Rose's pace a different impression is given. Rose is fully engaged with this interaction but I interrupt her at crucial moments, attempt to micro-manage the interaction and outpace her (Kitwood 1997). I am not giving Rose what she requires the most – time and silence; instead I attempt to move the story forwards at my pace.

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I have just given Rose a cup of tea and then ask her to “tell me about Manchester” (2). Rose is concerned with the roll of tissue on the table (1), I am not in her world and attempt to manage the conversation with an out of context comment. What is important to Rose is finding the tissue paper to enable her to blow her nose. She has located the roll of paper and remarks on her slow movements (3) which are further slowed by her left arm not being able to move. Rose continues to focus on the tissue and trying to tear off a sheet. Rose is interrupted in this focused activity when I suggest “that must be very frustrating” (5) to which Rose does not respond. In retrospect, I wonder why I thought that being slow is frustrating; I am clearly not in Rose’s world and am not able to conceive of slowing down to her speed without it being frustrating *for me*. Rose does not look frustrated, she is focused on the task of blowing her nose. In direct antithesis to the surrounding mobility of the ward, Rose is taking her time.

When I respond with contextual actions of taking the roll of tissue and handing over a sheet (7 and 10) Rose says that she wants to blow her nose. For Rose, embodied language appears to be taking a lead, with words in a supporting role. Enactment has assumed a greater role for Rose who has decreased use of words. The verbal narrating of the event has been substituted by bodily enactment (Hydén 2018). This requires the listener to suspend their normal conversational strategies and support Rose in her story. With close attention to Rose’s strategies of contextual movements, by slowing the conversation to Rose’s pace and using context the conversation can be supported, or scaffolded. With contextual actions, and by stopping to listen, Rose can be supported.

Rose becomes entirely focused on blowing her nose and then engages me into her world by looking directly at me (11); to which I respond with an out of context “Hello?” when perhaps silence was required; a meaningless intrusion into her world and Rose responds by looking at me briefly and then looking down (13).

Rose is reminded that there is a cup of tea but what I do not recognise is that Rose is looking for it on the table, which is cluttered and so it is not instantly obvious (17 and 18). Rose’s micro-quest for her cup of tea reaches its conclusion when she locates the cup and her movements become quicker as she starts to drink. Verbal conversation is stopped and we sit together while Rose drinks her tea.

Rose has spoken 19 words in just under three minutes; her embodied movements have said much more. However, inattention to her embodied language and not slowing the pace meant that Rose’s story was not supported or understood. Rose is clear what she is doing – wiping her nose and finding and drinking her tea. To understand Rose it is necessary to step away from the activity of the ward; to slow down and give notice to the small details. Rose’s micro movements are

telling a story which is now accessed through the medium of her body; her body has become an active, communicative agent, imbued with its own intentionality and purposefulness (Kontos 2005). Her responses through contextual actions are meaningful because they are bodily manifestations of self that persists despite her severe cognitive impairment (Kontos 2005). However in order to understand Rose time is needed to stand still and observe. A recognition of Rose's embodied language by those around her would enable her emotional and sensory domains of experience to be shared and understood, and enable her to remain connected to the world within which she is currently placed.

### 7.3.3 Bert

Bert's story is of personhood embodied in micro movement. It was an unusually quiet Friday at 5pm on the AMU. Most of the beds were empty and Bert was in a side room lying supported on a pile of pillows, dressed in a hospital gown which had slid off his right shoulder. He had a number of paper towels resting on his chest that he had been using to mop up drips whilst drinking. Muffled sounds of voices and a phone ringing came from outside the room, but Bert appeared unaware of these.

Bert worked his entire adult life as a dental technician in the same practice, and only retired aged 73 when the dentist died and the practice closed. Bert's face is relaxed and on reviewing the video I think that he looks comfortable as he lies against his pillows in bed. His right shoulder is not covered by the hospital gown and as I watch the video it makes me uncomfortable as I feel that his dignity is compromised. Bert, however appears unaware of how he is dressed. This position of his gown does, however, allow me to watch the movements of his shoulder as he speaks. I cannot see his hands but I think that they are resting to his sides just below the video frame. He doesn't raise them into view at any point, but I cannot say if he is moving his hands whilst he talks. What I can see are his shoulders which move slightly when he is focused on speaking to me – slightly tensing up then relaxing again. Bert's facial expressions are muted, the main movements coming from his mouth as he speaks and from moving his head from side to side and intermittently nodding. His voice is quiet and there are no distractions. I am sitting to his left.

Bert has just been trying to remember his date of birth, and told me that he was ninety four. He talks slowly and a bit breathlessly.

P: what's it like being 94?

B: Well

*Slight shrug of shoulder, rolls head to the right, then looks into the distance*

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B: the thing is I don't think people think you're worth bothering with

*Rolls his head and looks at me as says "bothering with"*

P: that's really sad. What makes you think that?

*Looks away from me, rolls his head towards the right then back to the middle and remains looking into the distance*

B: well I seem get run around from place to place, er and each different er

*Looks at me and slightly nods head*

B: each different ideas you know....

P: different ideas to yours?

B: yeah. What they're worth keeping or not you know

*Nods head; remains looking at me*

B: but I served my apprenticeship as a dental technician

*Stays looking at me*

P: as a dental technician? Did you?

B: yeah

*Slight nod and tiny right shoulder shrug*

B: and er there was um

*Looks away to right, blinks hard, swallows and looks into the distance*

B: I didn't retire until I was er..

*Looks at me and says firmly and quickly*

B: Seventy three

Bert's position is one of powerlessness; he considers that people think him not "worth bothering with"; but these words were amplified by his micro movements. During the course of our conversation, which took place in a quiet side room late one afternoon, Bert lay on his back in bed, his arms barely moving, his head movements slow, his eyes slowly blinking. There was a slow, sadness to Bert's movements. To consider another way of communicating enables a greater

depth of understanding. Bert may be causing no problems to care staff as he quietly lies in his bed; but his quiet demeanour means that he has been left alone, and “not bothered with”.

Bert is a dental technician, a position that he is clearly proud of and he went on to tell me about making over 3000 sets of dentures. He told of the “marvellous life with him [the dentist] we kept going all those years”; a life where he would have been in the background, working behind the dentist as an indispensable part of the dental practice. In Bert’s narrative he creates for me the person that he once was; a person that is clearly still an important part of who he is today.

Bert had been considering the injustice of having to wait for a denture appointment when he had spent his working life making over 3,000 sets of dentures. The fleeting and non-fixed nature of his small story was demonstrated when I knocked him of course with a complex and non-contextual question:

*Turns head towards me*

B: you know

*Looks away and nearly says something but I interrupt. Looks at me as I ask*

P: And just because you’re older do people acknowledge your level of knowledge?

*Nods and looks away into the distance*

B: Yes, oh yes

*Looks to right, back to middle*

B: but um anyway that’s my life really...

*Looks into the distance, sighs, swallows*

B: And er of course at the moment

*Sharp tilt of head towards right as shoulder lifts; stays looking into distance*

B: I’m living at home with me mother and sister and brother...

*Swallows, looks to right and back to middle quickly*

B: and er we manage

My question moves Bert away from his memories of working in the dental practice and leaves him searching for an answer. His eyes remain unfocused and his words and movements appear vague

and noncommittal until his memory arrives. Then his slow micro movements become quicker and he is back again living with his mother and siblings

## 7.4 Scaffolding, disentanglement and repair

### 7.4.1 Albert

Albert's story illustrates examples of scaffolding, repair and collaboration (Hydén 2018). The system wide macro movement had seen Albert moving from his care home, to the ambulance, to the emergency department, and finally to this bed beside the window. He had been admitted with chest pain, which was now resolved, and his notes said "severe dementia". He was sitting in a corner beside his bed, watching what was going on around him. Neatly dressed in a pale green shirt, blue cardigan and dark trousers, he told me he didn't have time to talk as he was going home. I said that this won't affect going home and we could chat right here, and that it might fill in the time. Albert was happy to do this. At the beginning I had trouble setting up the tablet which caused Albert to fidget in his chair, finally telling me that he needed to go to the toilet so we walked together and found one. He used a walking stick, and held onto me with his other hand.

The activity frame of this conversation was supportive – the bay was quiet, Albert was up and dressed, he had been to the toilet and he was not feeling unwell. During our conversation, Albert chose to talk about scuba diving, his time in the RAF regiment and ballroom dancing with his wife.

It was a privilege to slow down to Albert's speed, and spend unhurried time together; to really listen to what he was telling me. His medical notes had labelled him as "not able to say why here" and "poor historian" which struck me as interesting wording. The biomedical focus had been on what he could not do, and what he was NOT, rather than what he could do. I met a man who clearly was able to tell of his history, albeit not the medical history that may well have been expected by a clinician.

P: You were telling me about your swimming

*Slight smile, stays leaning back in the chair*

A: Scuba diving. I used to do scuba diving.

*Leaned back in the chair, body relaxed.*

P: Seriously?

A: I've done it at er Swanage, Weymouth my favourite place was Durdle Door. Do you know Durdle Door?

*Turns head slightly to left and looks up and to left as remembering. On his topic, closes his eyes to remember the places. Asks me the question using his eyes and slight inclination of head to left with direct eye contact and slight smile.*

P: I know it well. I live in Bournemouth so I spend a lot of time going over that way. I tend to stick more around Chapman's Pool and Kimmeridge though.

*Moves head back to the middle as he listens to me talking about Kimmeridge and Chapman's Pools and leans back with slight smile.*

A: Yeah. Well Durdle Door's my favourite spot. I've done dives, I've done scuba dives in abroad but I favour sw er Durdle Door to anywhere

*Slight nod as says "Durdle Door's my favourite spot". Moves towards me to bring me into his story then using his right hand and forefinger to re-emphasise his favourite spot. Points hard to emphasis Durdle Door; leans back to observe my reaction with a slight smile.*

P: why is that?

A: The underwater scenery is better.

*Leaning against chair back, slight nods of head to emphasise words.*

P: what do you see down there?

A: Well it's the seaweed, I mean when you see all the seaweed when the tides going it's a load of rubbish but when it's growing in the sea and you're swimming amongst it it's n it's I think it's lovely

*Relaxed face, still leaning back in chair looking at me; leans towards me in the chair; demonstrates the seaweed with sweeping right hand movements; looks at me and then uses both hands, eyes narrowed, brow furrowed when "swimming amongst it" and wide eyes looking directly at me with head slightly to left to emphasise "it's lovely".*

Albert continues for a short while to talk easily about scuba diving and seaweed, and then moves abruptly but comfortably into a story about his time in the Air Force; two areas where he is secure in his own knowledge base. Albert is able to scaffold his own story, moving freely through time and place. His body and face remain relaxed. I collaborate by listening unconditionally but then

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attempt to repair the story on my terms – to shift the story back to what I consider the main topic:

A: I couldn't afford it, not flying lessons, but in the Air Force I had umpteen blinking lessons

P: I bet you did

A: It didn't cost me a penny

P: fantastic. So you became a scuba diver. I'm really interested in the wild life around the coasts, so what sort of fish and...?

A: Fish?

P: yes, when you are out down scuba diving what sort of fish?

A: Oh it's a um mostly err mmm oh what's them common as muck umm ... the fish

P: is it wrasse?

A: There are wrasse. I see quite a lot of wrasse but there's another one that's

P: mullet

A: Is it something beginning with D, D? D D D D oooh what's it. Crumbs. Oh I've forgotten the blooming thing. Not mullet. Ohhh

P: I'm trying to think of a fish beginning with D.

A: Yeah. Oh crumbs. And I used to swim amongst them because it's very interesting to swim amongst fish because they don't go away from me they swim with you.

Not recognising the significance of the topic shifting to his time in the RAF, I throw Albert off course by returning to the scuba diving story. I feel uneasy watching the video with the sound off and then on again because it is only after several repeats that I recognise that Albert is inside his story of the Air Force and then I take him back to scuba diving. I do not recognise or acknowledge that his story has moved on or that my attempt at repair has been ill considered and wrecked Albert's activity frame – that of his chosen topic. Instead I am looking for my narrative, my interest in sea life. We attempt a joint repair of the narrative (Hydén 2018) by searching for the name of the fish that Albert used to see, but it is Albert who achieves the repair "and I used to swim amongst them....." and moves back into his story. Understanding of how this narrative exchange affects Albert comes only from close visual attention to his movements.

At first I think that the leaning forwards in the chair and the close attention to my words is due to his hearing, but I begin to realise that Albert is having to move his world from the Air Force into scuba diving and this shift is under my control. He has lost control of the narrative. His embodied language shows it:

*Albert's verbal fluency has disappeared and his face is now totally different. He leans in towards me. Eyes closed, face tense, his right hand trying to physically grasp the thoughts with tensed extended fingers; his head moves from side to side, face tight, he looks at me, there is no small smile playing on his lips now but a look of genuine concern; his right hand remains in the air with fingers spread and tense, hovering, not moving. He looks away to the right and then to the left and finally at me with narrowed eyes and furrowed forehead. His right hand is still raised, fingers stretched out he struggles to find the name of the fish. Unable to find the word, Albert uses gestures to attempt repair of the story. His right hand moves from side to side representing the movement of fish in front of him, then waves quickly from side to side as I suggest more fish names; he wags his right forefinger and looks away to the left, then looks up to the right as his hand drops to his lap. He cannot find the name of the fish.*

*He looks left and down to the floor, brows still drawn together, mouth downturned. The animation of his body has gone. He looks back up at me briefly and then away to the left as I say that I am also trying to remember the name of a fish; "crumbs" as he wipes his mouth with the back of his hand still looking off to the left; finally he falls back into his chair, looks directly at me, right hand rises off his lap and he has the memory! His memory.*

*He starts to talk fluently about swimming amongst the fish, he leans towards me, a small smile, eyebrows raised to emphasis his words; his face and body have relaxed, he uses a wide sweep of both arms to demonstrate the fish swimming with him, he looks at me and is smiling now, and then his arms relax down and he pushes his glasses up his nose.*

Attention to Albert's movements show how his embodied language works as another form of communication. His tense body and facial postures and sharp hand movements speak of discomfort and effort and how easily he can be thrown off course. This form of communication speaks of the work that is required to remain part of a social conversation with a stranger in an unknown place; even with an environment which is relatively quiet, and a conversational partner who is attempting to work with him to collaborate on the story.

At a later point in the conversation I ask "and how do you keep active now?" In order to answer this Albert has to focus on our interaction, attend to an abstract question, retrieve a memory and find words in order to answer:

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*Face falls; brows furrow; mouth downturned; leaning back in chair, hands in lap*

A: How do I what?

*Leans in towards me; brow furrowed, eyes narrow; looks at me*

P: how do you keep active now?

*Mouth moves slightly; leans slowly back in chair; looks up to right; wets lips*

A: Well that's just it. I do walk a lot

*Remains looking up to right; face still; mouth downturned*

A: And I still swim summer and winter

*Turns head quickly left to look directly at me, tilts head to right; eyes wide eye brows shoot up; inclines head; slight smile; nods*

P: Do you.

*Remains looking directly at me*

A: Cos I've always had a wetsuit

*Continues to look at me; rapid gestures with right forefinger;*

A: well that keeps you warm or keeps you comfortable in the winter.

*Opens palm and spreads fingers; looking at me; leans in towards me; two brisk downwards gestures with right hand; firm point with right forefinger on "winter"; leans back in chair*

Close attention to Albert's micro movements, particularly his facial movements, indicate his discomfort when I ask my question, and his comfort when he is on his topic – scuba diving.

His movements and micro movements also demonstrate the struggle to retrieve memories that are externally requested rather than internally produced. Albert first slumps into his chair, hand in his lap, face fallen; he has been lost by the change of direction of the conversation; then leans in towards me, his face expressing concern. His movements are slow, his hands still. His tense, frowning face lightens when he returns to his topic, and his movements become more rapid as he uses his hand to make quick, emphatic movements. Albert uses gesticulation to accompany and emphasise his spoken language when he is sure about the topic. At other times when his recall of a word is hindered Albert uses gestures to indicate the cognitive event of trying to find a word (Hydén 2018):

*His right hand moves from side to side representing the movement of fish in front of him, then waves quickly from side to side as I suggest more fish names.*

Albert's use of hand gestures depends on how comfortable he is with the topic of conversation. However, it is not only these gestures that indicate how comfortable, or not, he is in the interaction; his body position in the chair and facial expressions add depth to an understanding of the interaction. Taking part in this social interaction is hard work; collaboration and scaffolding (Hydén 2018) on my part is not always successful, but through an understanding of movement, Albert's comfort, or discomfort in the moment can be understood. What is understood can then be acted upon. However, Albert's narrative reveals how difficult it is to keep a person with dementia in a place of comfort, even when as in my case, I would consider myself to be reasonably well skilled.

#### **7.4.2 Ivy**

Ivy's story is a story of scaffolding, micro movement and self-repair. Ivy is 101 (nearly 102) and is on the AMU with an acute delirium. She has poor eyesight so cannot see fine detail. She was only admitted for one night and then went home with her daughter, Eileen. Ivy didn't really understand the tablet/video concept but readily agreed to have a chat. However, Eileen was happy for Ivy's data to be used as she believed that this is something Ivy would want.

Ivy is lying in bed with the head of the bed raised; dressed in a pretty patterned top, the sheet turned neatly down at her waist. Her hands are crossed on her stomach, she looks composed. Her white hair is neatly brushed. Unlike other participants, Ivy can move around her bed easily, giving the impression that she is there because she wants to be, and not because she is stuck. She demonstrates her grip strength<sup>5</sup> to me when I shake her hand and I am astonished at how strong she is. Eileen sits beside the bed during our conversation looking calm and smiling. Eileen does not speak much, instead supporting her mother with her presence and allowing Ivy to speak for herself. Ivy turns frequently to look at Eileen.

I pulled the curtains on either side of Ivy's bed, so although the back ground noise was awful, Ivy was only visually distracted when someone walked past the end of her bed (which happened several times). The noise in the bay was at times overwhelming.

Ivy had been talking about doing a paper round when she was thirteen years old and then had paused in her narrative:

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<sup>5</sup> Grip strength is a commonly used measure of global body strength for older people.

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E = Eileen; P = Researcher; I = Irene

E: can you tell Pippa where you used to live?

*Turns head on pillow; looks directly at Eileen*

I: I was trying to remember

*Moves head towards left, looks into distance; eyes wide; deep breath, turns head to Eileen*

I: I prob, I've lived in, I did live in Newcastle on Tyne.

*Looks at Eileen; slight frown; hands on lap*

I: Yeah my husband was chasing a promotion and of course you got sent to a different town.

*Turns head, looks at me; head off pillow; fingers wagging right hand, rests right forefinger on left middle finger; other fingers continue to move; inclines head slightly to left*

P: Right

I: So Newcastle on Tyne probably give you about 3 or 4 years

*Looks at me; counting off places on fingers*

P: yup

I: Um

*Looks up and away; head back on pillow*

I: London of course

*Head off pillow; looks at me with slight nod of head; glances at Eileen*

I: Liverpool

*Looks at me; definite nod of head*

I: That's right

*Fingers interlocked; looks at me, slight emphatic nod*

I: and I had home and Glasgow very much Glasgow

*Looks at me; eyebrows raised, fingers of both hands stretched out, hands lifted off chest gesturing*

I: Very much Glasgow

*Briefly points at me with right forefinger*

P: gosh you really have travelled around. Where was your childhood?

*Looks at me; clasps hands on lap*

I: my husband was err a scot

*Slight nod of head; looks into distance*

P: oh was he

I: he was born in Banff? That right?

*Says "Banff" firmly; Breath in; turns head to Eileen; hands clasped on lap*

E: yes he was.

*Turns head to look at me, swallows; Eileen places her hand over Ivy's, smiles and nods*

E: well done

Eileen is scaffolding her mother who she knows well. She sits on her mother's right hand side, close to the bed and directs her gaze from Ivy to me as we speak to each other, using gaze to scaffold turn taking (Hydén 2018). At times Eileen nods and smiles slightly, validating the content of her mother's words, and speaking quietly and calmly on the few occasions where she speaks.

Eileen suggests the topic by asking where Ivy used to live, perhaps a subject that Eileen knows is familiar to Ivy. Initially Ivy tries to remember, looking into the distance, unfocused at first then turns to Eileen for scaffolding. Eileen looks at Ivy throughout this exchange but does not fill in for Ivy, instead allowing Ivy time to find her own story. Once Ivy has her story her hands become animated, her head lifts off the pillow, she nods and moves her head. Eileen validates her recall of where Ivy's husband was born with a smile and hand touch. In a similar way to Albert, Ivy uses hand gestures to support her words when she appears to be comfortable with her topic; her gestures at these times appearing purposeful.

Ivy's micro movements that accompany the process of recalling are less comfortable when I suggest the topic. Ivy has just mentioned her paper round, a topic that she returns to four times during the conversation. Part of this story is about a man who exposed himself to her. Following a pause, I clumsily attempt to scaffold the conversation, and move away from the paper round, and ask:

P: how long did you stay in school?

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*Looks into distance*

I: well from all my school years.

*Looks into distance blinking, not focused; hands on lap*

I: Mum had a cottage in [names place]

*Slight frown; remains looking into distance, slight nods of head, hands on lap*

P: and is that somewhere you used to visit or

*Looks towards me; swallows;*

I: that's when we lived with my mum.

*Nods; remains unfocused looking into distance*

I: That must be before we were married.

*Unfocused gaze into distance; hands still on lap*

I: I've lived in I've lived in Newcastle upon Tyne

*Nods head; lifts head slightly off pillow; turns eyes towards Eileen*

I: I've lived in at home

*Looks directly at me; lifts head off pillow; emphasises home with both hands briefly lifted from chest*

I: and Lon and London.

*Slight nods of head; hands on chest*

I: Where else?

*Turns head quickly to look directly at Eileen*

Ivy's gaze remains unfocused and her hands do not move whilst we are on a topic that is chosen by me about her school. On rewatching, I recognise that I move the conversation on (towards my narrative) because I feel uncomfortable about Ivy's revelations of the man exposing himself to her when she was a child. Ivy attempts self-repair by gradually constructing her own story, moving from her school years, to her mum, married, Newcastle and finally to her own memory "I've lived in at home". At which point Ivy looks directly at me, both her head and hand movements become decisive and then she turns her head to look directly at Eileen to request scaffolding.

In order for people to do something together they need to cooperate and coordinate their attention by focusing on the same thing; focus on what is said or done leading to an understanding and then an uptake (Hydén 2018). In Ivy's case she was successfully supported and scaffolded by Eileen; however my attempts lacked sensitivity and on reviewing the video I recognise that I am looking for my narrative, not Ivy's. Against a background of loud noise and movement of other people, Eileen is able to support Ivy within her story; my attempts show just how easily a person can be thrown from a position of comfort by an ill judged question.

### 7.4.3 Philip

Philip's story is one where scaffolding and collaboration are missing. Philip is sitting in a chair with his wife Mabel nearby, it is noisy and hot and Philip is dressed in a hospital gown. He has been admitted to the AMU because Mabel has suddenly started falling over and a brain tumour is being queried. Mabel does not know this. Philip cannot be left alone at home, so despite having no acute medical needs, the ambulance crew brought him along and he has been admitted. He has sat in a chair all night beside Mabel; he got a bed early in the morning, but got into Mabel's instead. They are waiting for an emergency respite bed to be found. Mabel is clearly anxious about their situation, but is keen to take part in the study as she welcomes the distraction for both herself and Philip. Talking with some of the therapists after the video we tried to estimate how many people had interacted with the couple since their admission 18 hours previously – as a pair they have had more interactions than a single person. We estimated 29 people.

I am unable to video them both due to the angle of the frame. Mabel sits to Philip's right, and takes part in our conversation. I explained the study to them both and they both wanted to take part. Philip seems to pride himself in making independent decisions; Mabel is apologetic for him "he forgets a lot", "he doesn't remember". However Philip clearly wants to take part in the video. At the end he is not sure about looking at it.

Unlike Ivy, who was quite mobile within her bed, Philip portrays to me a sense of "stuckness" (Hage 2009). Stuckness is by definition a situation where a person suffers from both the absence of choices or alternatives to the situation they are currently in, and an inability to grab such alternatives even if they are present. Philip is leant back in his chair which is next to a thoroughfare; people constantly walk up and down to his left and talk loudly across him to people at the nurses station in front of him. Alarms are ringing from bedside monitors; conversations are loud; people move back and forth and around us. The activity frame for our conversation could not be worse.

Ph – Philip; M – Mabel; P - Researcher

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We are in the middle of a conversation after one such interruption:

P: OK you were going to start telling me Philip ..

*Glances left, turns head slightly left*

**Man walks past. Nurse calls loudly across Philip "I'm doing bed managing"**

*Back to centre; turns head quickly left, centre, brows lowered*

M: Pippa's talking to you

*Turns head and eyes right; turns left, centre, eyes wide; turns head right fast, eyes shift right, left*

**Nurse loudly, across Philip, to someone at the nurses' station "I need to speak to you"**

*Turns head to right, looks at nurse, brows tightly furrowed, mouth down; quickly turns head right, eyes shift left*

**Nurse walks off talking loudly over her shoulder "I'll speak to you"**

*Looks at me, then down, briefly shuts eyes; looks straight at me, eyes wide, brows furrowed*

P: I hear you've been married for 50.....

*Eyes wide, lowers chin, eyes glance left, brows furrowed; glances at wife, then me, eyes wide*

Ph: I'm sorry I'm listening to what's going on around me

*Pulls back in chair, briefly laughs; brows drawn, eyes looking at me; stops instantly,*

P: absolutely it's a lot going on, it's difficult

*Turns head left, right; looks at Mabel*

M: yes its 57 years this December

*Head and eyes still; brows less furrowed; mouth twitches*

M: ....we've been married...it's a long time

*Looks at me, eyes glance right*

P: that's fabulous

*Glances at me; looks at Mabel, glances at me*

P: does it feel like a long time?

*Head still; looks ahead, mouth downturned, eyes look right; scratches cheek with right forefinger, brows furrow*

M: Yes. Does to me ..... does it feel a long time to you?

*Looks at wife; swallows*

Ph: yes, not long enough

*Inclines head to right; remains looking at wife, raises eyebrows*

M: no we're gonna keep going on

*Briefly hunches shoulders; turns head left, swings head round to right and up*

Unlike Ivy, Philip has no scaffolding. His wife who he has known for 57 years is unwell and anxious. I do not know him. The video captures Philip's activity frame which is noisy, with constant movement on his left and in front of him. Philip is aware that Mabel and I are talking but a nurse shouts across him loudly and he cannot hear us. Philip apologises for not participating "I'm sorry I'm listening to what's going on around me". Mabel attempts to scaffold the story by filling in for Philip, and the result is that she and I take over the activity and Philip is not part of the conversation. The effect that this is all having upon Philip is shown by attention to his micro movements. He makes 24 head movements, left, right, up, down and forwards, with his eyes flicking around to follow the noise and movement. His brows are tight and furrowed and at times he closes his eyes. Apart from scratching his cheek, his hands do not move.

Philip's micro movements bring understanding to how his environment is effecting him. The work that is involved in taking part in this interaction are apparent from the rapidity of his movements. Yet when viewed briefly by the staff passing by he appears as a man "stuck" in the chair amidst all this commotion; the communication of his micro movement is lost on the casual observer.

Later in the conversation Philip articulates his sense of stuckedness (Hage 2009) and his inability to go home. Mabel has just been talking about waiting for a brain scan and wanting to go home:

*Leaning back in chair; hands on lap; elbows on arm of chair*

M: and Philip wants to get home as well..... don't you?

*Looking towards nurses' station; brow furrowed; hands on lap; mouths slightly open*

Ph: sorry

*Turns head sharply right; looks at Mabel; raises eyebrows*

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M: you want to get home as well

*Looks at Mabel*

Ph: not half, please.... I'd even walk

*Turns head briefly left; raises eyebrows; chuckles; looks down; looks at Mabel, inclines head and raises eyebrows; drops head back, chuckles; wide smile*

P: (laughs with Philip) Do you live close enough to walk home?

*Stops smiling; looks at me; raises eyebrows*

Ph: I do, yes

*Eyes wide; brief nod*

M: we live in [names place]

*Looks at me; frowning; eyes glance at Mabel*

P: [names place], right, so it would be quite a step to get home

*Looks at me*

M: it would

*Looks at me*

Ph: no it... I'm not disputing that.... I'm willing to try .....

*Shakes head keeping eyes on me; brows drawn; tucks in chin, grimaces; looks right to follow noise; looks at me; brows furrowed, eyebrows raise*

P: to get home

*Looks at me; blinks; Slight lift of chin;*

Ph: yeah...please. I'd much rather work in my garage, shed call it whatever you will

*Chin tucked in; eyebrows knitted together; mouth downturned; eyebrows raise briefly; eyes look left; head turns quickly left; slowly back to me; frowning; eyes looking down and left*

Philip is a big man and fills the space; his hands rest passively on his lap throughout the exchange. This is a man who speaks of movement and action, yet is stuck in this chair. "Do you want to go home?" "[N]ot half, please.... I'd even walk"; "yeah...please. I'd much rather work in my garage,

shed call it whatever you will". His current situation has left Philip with no choice, he has to accept inaction.

Philip's passive posture in the chair belies the intensity of his micro movements. This is not a passive man sitting in his chair, this is a man constantly on the move. His head and eyes are constantly moving: left, right, forwards as he follows the noise and action around him. Even in this short moment of conversation he frowns, smiles, laughs, moves his head, mouth and eyes. He is never at rest, and watching the video again and again, I believe that he is exhausted.

All this chaos and noise is not lost on Philip, who with complete clarity and succinctness comments at one point:

Ph: Bit like commercial road on a Saturday. Commercial road is a tahh...is it .....

M : Portsmouth is that where you're thinking of?

Ph: I don't mind where it is (laughs) but it's usually tremendously busy, lots of buzz buzz buzz going on and.....not much intelligence

Sometimes an understanding can be reached by simply looking beneath the surface of the words to what is happening for the person in that moment in time. Philip could not have been clearer.

## 7.5 Summary

This chapter has at its heart the noticing and interpretation of movement.

Through the ten narratives I have demonstrated a form of research practice that is attentive to movement and micro movement, showing that through the lens of movement personhood can be reconsidered as a mobile process.

The words of each participant, whilst important were shown to reveal only one layer of understanding of the person. Consideration of the accompanying conscious and unconscious movements – the embodied language of each participant - led to a deeper understanding of each narrator in that moment of time.

Jane, with her constant movement, and a narrative that came in fragments, illustrated the work needed to maintain personhood in a chaotic world; David's narrative from inside the chaos showed that attention to an embodied narrative requires letting go of the personal narratives of the interactional partners. Brenda's pointing finger and curled up body showed a truth that was stronger than words.

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Arthur showed how his embodied personhood as a naval man was scaffolded by his body movements and bed making; Elizabeth was holding onto a sense of self against the background of noise and movement. Both illustrating personhood as a mobile process.

Rose is a person on a micro quest – slow movements in a sea of activity; whilst Bert, with minimal movements, quietly narrates how he is not worth bothering with. Albert talks of movement and action, whilst his embodied language show how easily the maintenance of personhood can be thrown off track by others.

Ivy showed me how easy it is to turn a conversation when the content becomes uncomfortable for the listener; and how well a person can be scaffolded through calm and supportive micro movements and words by someone who knows them well. And Philip was left unsupported by a wife in crisis and made invisible by the movements of others around him.

Throughout all the narratives the context of the AMU intruded and shaped the way that the stories were told. The macro movement of the AMU environment, and the soundscape produced by this movement, creating barriers to effective communication for people already disadvantaged by illness and dementia.

## Chapter 8 Personhood as a mobile process

*“There has been an odd diminishment of the status of storytelling in medicine ever since we decided we knew enough about the body by virtue of reducing it to its parts that we did not need to hear out its inhabitant”.* Charon 2005

This chapter builds on the findings from the previous two chapters by bringing together the different fragmented elements of the narratives into a narrative whole. I will do this whilst keeping at the forefront of my mind that “good narrative research persuades readers” (Riessman 2008 p191).

When a person with a dementia diagnosis is admitted to an AMU at a time of medical or social crisis, and having already experienced an ambulance transfer, triaging on arrival, at least four hours on a trolley and a transfer to the AMU, they are generally exhausted and stressed. Close narrative study of single cases, as in this study, can display how larger social structures insinuate their way into individual consciousness and identity, and how these socially constructed “selves” are then performed for (and with) an audience, in this case the listener (Riessman 2008 p116).

The participants in this study demonstrate that either individually or in collaboration, they are working to establish and maintain their personhood whilst actively seeking meaning. This is being achieved in the hypermobile AMU where contact with others is fleeting and mainly tasked orientated; the participant is in medical or social crisis; people around are unfamiliar, and familiar modalities such as walking up and down stairs, or going to the shops are absent.

This thesis has both empirical and methodological findings. Empirically, the study has sought to broaden the concept of movement and mobility as it applies to people who have dementia on an AMU. The current consideration of movement for patients within a hospital is narrowly confined to walking, transferring and functional activities. This research has shown that movement is not only how a person moves from A to B, but is inherent in all aspects of being a person. From the mobility that is experienced by people and things moving around, to the micro movements that are made without conscious knowledge and which are the manifestations of embodied language, and through which personhood can be maintained and reflected.

This study has addressed the following research questions in Chapters 6 and 7:

1. *What narratives are shared by a person with moderate or severe dementia in social or medical crisis when they are an inpatient on an acute medical unit?*
2. *Does a mobilities lens help in the understanding and interpretation of these narrative?*

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In addition to continuing to consider questions 1 and 2, this chapter will also address the following methodological research question:

*3. How can people with moderate or severe symptoms of dementia be enabled to contribute to the research agenda in acute hospitals?*

This has been a Clinical Doctoral Research study and as such I will consider the methodological and narrative findings from this study, and clinical implications, from the point of view of both a clinician and a researcher.

### **8.1 Social citizenship in research – the EXPECT agenda**

The following discussion is organised through the lens of the EXPECT framework that I introduced in Chapter 2. The EXPECT framework applies a social citizenship lens to the research process with particular emphasis on meaningful participation and freedom from discrimination.

This thesis has utilised the social citizenship model (Bartlett and O'Connor 2010) as its underlying principle. This recognises that people with dementia not only are influenced by interpersonal and social relationships, but that they also influence these dynamics because they have agency.

Importantly for acute hospitals, this model places people with dementia as active agents in their own rights, and not solely people who are part of a carer/cared for dyadic relationship. People are also husbands, wives, workers, friends, parents, advocates and activists. They are citizens of our society, including the society that is found within acute hospitals.

With particular relevance to this Clinical Doctoral Study, Bartlett and O'Connor social citizenship model (2010) also proposes that we reconsider what we regard as evidence and should expect people to be actively involved with research if they so wish. This is framed within the EXPECT agenda which is used here as the heuristic framework within which the findings from this study are brought together and discussed.

The EXPECT agenda is summarised in the box below and the following sections are based on the six elements of the framework:

Evidence-based practice reconsidered: privileging people's stories

eXtended research agenda: beyond health and social care quality

Participatory and creative methods

Ethical debates and dilemmas

Critical Lens

Translation of research into practice

The previous chapters have shown that people with dementia on an AMU have narratives to share, and that attention to their embodied language in the form of movement and micro movement reveals personhood being constructed as a mobile process.

These findings are explored further under the following headings. "Evidence-based practice reconsidered: privileging narratives" considers how narratives can reveal a person's embodied personhood. "Extended research agenda" looks beyond simply care-related issues to consider the person within the sociocultural setting of the AMU. "Participatory and creative methods" discusses methodological findings and insights. "Ethical debates and dilemmas" considers matters of capacity, consent and inclusion. "Critical lens" critically considers the process of data collection and analysis in the context of the AMU. "Translation of research into practice" considers the implications of this research to acute healthcare.

## **8.2 Evidence based practice reconsidered – privileging narratives**

The narratives that were shared have led to the recognition of the importance of embodied language in the understanding of personhood on an AMU. To work within a paradigm of embodied narrative is not to study anything new or different, but to address familiar events and topics, such as the stories told by people on an AMU, from a standpoint that includes the embodied process as part of the overall message (Bresler 2006). However, despite that there is a corpus of theoretical work that considers bodies, embodiment and affect, less work has taken place on the task of grappling with how we translate these theoretical insights into concrete methodological tools and approaches (Chadwick 2017).

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Considering narratives only in terms of what they are about can cause identity to be depicted at the representational level of speech activities only; by including the performative interaction that takes place in everyday talk, embodied narratives can be conceptualised as playing an important function in the formation and navigation of identities (Bamberg 2004, 2011) and personhood.

Merleau-Ponty (1962) recognised that body language can be used in the projection of status and identity, and theorised this as the pre-reflective body that does not require a cognitive form of consciousness. Merleau-Ponty argued that this pre-reflective body is in itself intentional and capable of performing actions that are inherent to the body, and distinct and apart from conscious action. Thus taken as a separate entity, embodied language can reveal a truer picture of a person's feelings because they are not mediated through the conscious mind. A consideration of this form of communication is therefore well suited to understanding the narratives of people who find verbal expression and retrieval of memories problematic.

Expecting to understand the personhood of someone with dementia only through their use of words is to "overlook how bodily sources of agency, grounded in pre-reflective level of experience, are fundamental to the constitution and manifestation of selfhood" (Kontos 2005 p555). However clinical practices, and biomedical narratives in particular, are premised on a model of dementia that denies the body an agential role in the constitution and manifestation of personhood (Kontos 2005). Viewed through the lens of social citizenship, dementia care practices must begin to understand and embrace the significance of embodied narratives in order that personhood can be supported.

Through the narratives that have been shared, this study has shown that as Kontos (2005) contends, treating the body only as a medium through which personhood is portrayed by words, effectively denies the body any intentionality or agency separate and apart from cognition. When movements and micro movements, as well as the words, were taken into account, the narratives revealed layers of meaning which could be envisaged as the participant making meaning from their environment and establishing their personhood, both consciously and unconsciously.

These narratives from the AMU can be reconfigured as a series of layers; each layer part of, but also separate from the other. The first layer is the words. The person telling their fragmented story is framed as the "untrue" patient who does not fulfil their role as thankful, earnest, obedient, and honest (DasGupta 2006). In the biomedical narrative they are labelled as "confused", "not able to say why here" and "poor historian"; their narratives are not attended to and stories are made up about them.

Yet a rethinking of our hypercognitive (Post 2000) view of memory as a conveyor of truth and lies, leads towards a consideration of how words can be used to scaffold and create a sense of self. Attention to the stories told on the AMU show people with dementia who are actively seeking and making sense of their situation, whilst also establishing their personhood.

Through her entangled narratives (Hydén 2018) Elizabeth sought to establish her identity through stories of her life in France with her husband. Her words portrayed an independent, bilingual, musical woman who was also a devoted wife. This story was told against a background of intrusive noise and the movement of many people that Elizabeth could see and hear as she sat in her chair. The first layer of her story is a restitution narrative where she restores her former self to me with her words; what was experienced becomes experience in the telling and in its reception (Frank 1995).

The power of Roger's story came from the words that he spoke. Roger was aware of being labelled by his dementia which had led to his malignant social positioning (Kitwood 1997) by the people around him. Roger was the only participant who directly referred to his diagnosis of dementia, and the importance of this diagnosis was not how it affected him as he lived with the condition, but how this diagnosis made other people behave towards him. This behaviour of others became Roger's reality through which he had to "maintain his sense of self against the odds".

Albert told me of his scuba diving. An incongruent story of nature in a place filled with hard edged medical equipment and strangers. A narrative of resistance, a story that resists the identity of passive patient or care home resident, but instead tells of past events that are imbued with mobility, movement and action.

The narratives that were shared are not of a person with dementia who is acutely unwell, maybe because people recognise that they have no authority in deciding what is significant about their case or to legitimate the actions of others (Latimer 1999). They are not permitted to participate in the authoring of their wants and needs, or in the making up of their clinical identities in any direct way (Latimer 1999); they are positioned as passive recipients of another's care. Thus, with no support or scaffolding from the context in which they find themselves, stories present one way in which individuals can create and hold onto a sense of personhood and identity, to form some foundation in the moving world of the AMU around them.

Kitwood (1993) recognised that at times words are simply an accompaniment rather than the vehicle for carrying the significant message. Treating a narrative primarily as words, and not as a

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collaborative and embodied activity therefore imposes limits on how the story can be understood (Hydén 2018) and by extension, limits how personhood can be understood and upheld.

The second layer of narrative meaning, therefore, is the use of conscious body movements in the form of gestures. Instead of gestures accompanying words in a story, gestures can take the lead role with words only stressing or supporting bodily gestures, or gestures may even replace words entirely (Hydén 2018). This implies that the verbal narrating of an event may be partially or totally substituted by bodily enactment (Hydén 2013).

In this study, gestures were used to support words and were used most often when a person was confident on the topic of their conversation; and became less used on topics that had not been chosen by them. In themselves, gestures appeared to either substitute for a word or add emphasis to a word or sentence.

When Albert was confident on his topic of scuba diving he demonstrated the seaweed with sweeping right hand movements, looked at me and then used both hands to indicate swimming amongst it. His gestures mirrored his words as he asks me a question using his eyes and slight inclination of head to left, with direct eye contact and slight smile, using small nods of his head when considering the underwater scenery. Albert also used gestures to attempt repair of the story when searching for the name of a fish. His right hand moved from side to side representing the movement of fish in front of him, then waved quickly from side to side as I suggested more fish.

Ivy also showed how gestures could be used to indicate whether a person was comfortable with the topic or not. When relating the places that she had lived, Ivy used both hands for emphasis and to count place names; when not on a topic that she was comfortable with, Ivy's hands remained clasped on her chest and barely moved. Brenda's outstretched finger that pointed accusingly at me and her carer left no doubt of its intention – she held me and her healthcare assistant responsible for her positioning.

Roger used his jabbing forefinger to emphasise his words, portraying suppressed anger. Roger had already been labelled as aggressive and perhaps this restrained action was indicative of his awareness that he needed self-control if he was ever to “get out” of the AMU and go home. People work hard to prove that they are a worthwhile patient, or as Latimer (1999 p186) puts it “older people are committed to their inclusion in the medical domain because their association with positive medical categories helps them keep at bay the inchoate, the dark at the bottom of the stairs”. Inclusion in a positive category is itself judged by reference to how a person conducts themselves, both in the present and in the past. Maintaining a sense of self against the odds thus

also becomes a way to prevent marginalisation and enable inclusion; inclusion in a positive category appeared to be what the participants were consciously, or unconsciously striving to achieve.

Attention to the conversational strategies of people with dementia has considered non-vocal communication such as body posture, pointing and facial expression as an adaptive strategy and adjunct to verbal communication (Kindell et al 2017). Yet this second layer of narrative is perhaps less informative of the person than is the third layer – the pre-reflective unconsciously embodied language. It is this layer of narrative meaning that is revealed through close attention to movement and micro movement.

Movements do not only support the words but in some cases tell a different story altogether. Looking at micro movements and movements you discover a truth about a person's needs, identities and emotions in that moment; "the tangle of values, meanings, choices, desires, and loves in this particular life" (Charon et al 2017 p111).

Jane's frenetic movements of her face, mouth, body and hands mirrored the chaotic world around her, and perhaps the chaos in her head as her words jolted from topic to topic with no sense of unity. When chaos is lived there is only the immediate moment; the person "is imprisoned in the frustrated needs of the moment" (Frank 1995 p98). Thus, the true chaos narrative cannot be told but can only be lived, the voice is subsumed by interruptions, interrupting itself as it seeks to tell (Frank 1995). As people moved across in front of Jane's field of vision her eyes moved left, right, forwards, left; flicking ceaselessly as her head also turned quickly to follow movements and sounds.

Elizabeth moved back and forwards in her chair, her face tensed and anxious, never still, whilst attempting to present her sense of self to me despite the moving scene in front of her. These bodily narratives belied her words of independence, intellect and a lady who copes. Her micro movements revealed a lady struggling hard to overcome the noise around her, to make social contact in a way that created a positive impression and to make sense of the here and now. Underneath her exterior there was a lady really struggling to survive in that place and in that moment. Her embodied language was telling the truth.

Micro movements are indications of conflicting emotions, emotional control, discomfort, effort and the work needed to be a patient in the AMU, whilst also maintaining a sense of meaning and self. This standpoint attends to the embodied process of the narrative event as part of its overall message and opens the possibility of discovering the others' horizons and thus accessing other's ideas (Bresler 2006) even when that person cannot articulate their horizons verbally.

A person's identity can be seen to be formed in stories that create some form of meaningful whole out of different phases of one's life by integrating the past and present events into a story (Baldwin 2005). The past events are articulated, with different degrees of ability, by words, but the present that the individual is experiencing is conveyed by their embodied language which is only apparent, and understandable, in this context at this time. The individual can be shown that they are valued and understood, by contextualizing the story currently being told, and using this story, however it is conveyed, to gain an insight into what is happening in the present. Through understanding embodied language through micro movements, meaning can be made by the observer.

As Frank (1995) recognises, the fact that the teller's body shapes the illness story should be self-evident, and stories should be understood as being told through the body and by the body. These narratives show that even with a considerable degree of dementia, people are maintaining their personhood and negotiating their place within the AMU, and it is only by eliciting these stories in context, and attending to their embodied language in the form of micro movements, that this can be understood.

### **8.3 Extended research agenda**

The "Extended research agenda" looks beyond simply care-related issues to consider the person within the sociocultural setting of the AMU.

This section critically considers the interplay of individual subjective experiences and the context of the AMU through the lens of mobility. Research that examines conversation with people with dementia provides a rich source of data to not only explore the challenges of communication for those taking part, but also the skills retained by the person such as eye contact, turn taking and "embodied behaviour" (Kindell et al 2017). Although Kindell et al's (2017) literature review outlined a broader view of communication that did not rest solely on the transfer of information, as in the biomedical narrative, and acknowledged its place in enhancing social connections, it did not include examples of people in acute hospitals. The studies included in the review were all undertaken in environments that were familiar to the participants such as homes or care homes. This study is unique as it considers people in the unfamiliar environment of the AMU.

There is a power dynamic in the hospital that is made visible through a lens of mobility. As the threshold of the hospital is crossed one person becomes an empowered and mobile professional; the other is placed on a trolley, their clothes are replaced by a gown and they are rendered by their supine position, immobility and lack of autonomy, as totally dependent on the staff around

them. Through an envisioning of mobility, elements of Kitwood's (1997) malignant social psychology can be observed.

Philip is rendered so powerless as to become almost invisible as the nurse shouts across his conversation to a colleague at the work station. Even Roger, who recognises where he has been placed by the clinical world, lies in his bed in an embodiment of resignation, if not complete acceptance of his powerless position. How and why do people fall into line and accept their lack of control and autonomy?

Personhood is a mobile process. The way that we feel about ourselves and our sense of self is not fixed and rigid, but can be seen as something that resides in the arrangements prevailing in the social system; the self in this sense is not a property of the person to whom it is attributed, but dwells rather in the pattern of social control that is exerted in connection with the person by those around him (Goffman 1991). Once a person has been placed in or beside a hospital bed in a gown or pyjamas, not enabled to go home as in Roger's case, or talked across as in Philip's, their social positioning is made physically clear by the attitudes and behaviours of healthcare staff. Even with cognitive problems, people are able to recognise this and "keep their heads down" and avoid being problematic.

The world of the AMU is a world of mobility where social encounters are many and fleeting. In each of these contacts, a person tends to act out a pattern of verbal and nonverbal acts by which they express their view of the situation (Goffman 1990). By referencing back to earlier life events in order to make sense of the current situation, Philip talks of the Commercial Road on a Saturday which is all buzz, buzz, buzz and not much intelligence; his micro movements show a man constantly distracted by passing people and loud voices, unable to fully participate in the conversation from which he becomes excluded. He is a man who has been disempowered by the hypermobility of the ward around him, but he demonstrates that the rushed and task orientated care processes do not pass unnoticed and he is aware of, and annoyed by, the lack of meaningful interaction with ward-based staff (Prato et al 2018). With reference to a long stay ward, Nowell et al (2013) described how people with dementia adjusted both their expectations and feelings about the system to fit the system, rather than the reverse being true.

For people who are becoming less verbally fluent, micro movements can give indications of their reality. Rose is completely outpaced by the mobility that is around her. She seeks to make meaning out of this place of strangers, and wonders why she is down here, in this town and not in Manchester where she knows people. "Why am I here?" she wonders out loud, her voice tearful. Later her micro movements reveal a lady on a quest for her cup of tea and a tissue; yet the world around is so fast moving it fails to notice that she is thirsty because she can't find her cup on the

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cluttered table. There is power in all this hospital movement and it is not in Rose's one functioning hand.

David, in his world of chaos, with no support or scaffolding, struggles to make sense of his place within the AMU. Surrounded by people who are trying to get him to do something that he does not want, David hits out at those who are attempting to grab him and tries to move away. His face and movements suggest that his reality is frightening, but his reality is not recognised by those around him. David is viewed simply as a person at risk of falling over and needing to be restrained. Rules of the system within which people find themselves are not always explicit, and may be inherent within the system, but can be confusing or upsetting because they remain unspoken and unique to this particular environment (Nowell et al 2013). Viewed from the outside, David did not appear to understand what was happening to him, let alone why.

Despite being positioned powerlessly by those around them, people on the AMU still worked to maintain their sense of self and resist the patient identity. Interactions with other people are only one aspect of the immediate environment within which the person with dementia interacts; there are other aspects such as the use of physical space and the engagement in activities which also provide interactional opportunities which can either add to, or detract from a person's sense of identity (Bartlett and O'Connor 2010).

Arthur used the space around his bed to enact his naval days and hold onto his sense of self. Without scaffolding and alone, he used the movement of bed making, and through this he performed his reality, that of a naval man making his bed. His conversation reflected his movements as he talked of his past and how things had now changed, and not necessarily for the better.

Being positioned as immobile in a hypermobile place creates an additional stigma for people with dementia on an AMU. They are also stigmatised by declining cognition in a world that rates cognitive ability highly; immobile in a place where mobility is associated with business, purpose and profession; older age and not able to tell a biomedical story. This accumulation of stigma means that an individual who might in the past have been received easily into social connections, now becomes stigmatised and the stigma become the understanding of the person (Goffman 1963).

Shifting attention from discursive to social functions gives recognition to people who have difficulty verbally expressing themselves. The clinical relationship with people who are not able to utilise language and retrieve things with words needs to be reconsidered: without a consideration of a communication which is beyond words, those of us in healthcare cannot connect with each

other, or understand where we are in the moment of the interaction. Personhood is at risk of becoming lost.

Curled up on her side in bed, Brenda had been understood as the sum of her stigma, prevented from moving due to safety concerns, not engaged in conversation due to her cognition, her decisions around which socks to wear over ruled, and no attempts made by her 1:1 nurse to find out more about her. She had become dependent on the attitudes and subsequent behaviours of individual staff members, yet both had an impact on the other that could be traced through the stories that held them together – you are part of my story and I am part of yours (Baldwin and Greason 2016). The healthcare assistant's story was "she keeps running away" and she would not wear the red non slip socks which was assumed as a wilful stance; Brenda appeared to have taken into account this response to her actions and had curled up away from the carer. Neither understood the other.

The space at the bedside has not emerged as a collaboratively managed space because patients have no authority in deciding what is significant about their case or to legitimate the actions of others (Latimer 1999) because they are labelled and stigmatised. Additionally, people are not permitted to participate in the authoring of their wants and needs, or in the making up of their clinical identities in any direct way (Latimer 1999) because their form of communication is not being recognised.

Attention to narrative shows people who are constantly communicating, holding onto their identities and demonstrating emotional agency through movement and micro movements. Sometimes support is available - Ivy calmly supported by her daughter, whereas Elizabeth attempts self-scaffolding with huge effort which is shown by her embodied language. This introduces another possibility for the narrative - that of shifting the emphasis from the discursive story world to the social functions of the story. This shifted focus can then enhance the relations between the participants, by attending to bodily resources like touch, eye contact, facial expressions and movements (Hydén 2013).

Meaning must be given to these narratives because people are searching for meaning: believing they are a son living with a mother; a scuba diver; believing they are in a different place; convinced that a person is still alive; believing they are engaged in a task relating to a previous occupation; wishing to leave and go home. We need to be able to understand these experiences in order to be able to connect with the person beside us. People are working hard to be part of the world around them; we need a deeper and more sensitive understanding of this.

Dementia can profoundly affect our core identities, our relationships and our 'being in the world', and cause a myriad of responses in those around (Mental Health Foundation 2016). Keeping the individual in focus and recognising that experiences are often unique to each individual, limits the scope for general messages, but increases scope for understanding each person separately.

Remembering and recounting accurate experiences and relaying them in a coherent narrative becomes less important when narratives are considered as multi layered and textured performances that need to be unconditionally accepted, and sensitively translated on an individual basis.

### **8.4 Participatory and creative methods**

"Participatory and creative methods" presents the methodological findings and insights from this study.

The AMU presents a unique environment where interactions are short and multiple, the pressure to move patients on to another ward or to be discharged is high, and patients have acute medical or social problems. Therefore to conduct research with people who have generally been perceived as vulnerable in this environment presents a number of challenges. Yet we know that the detrimental effects of admission that were considered in Chapter 2 can happen in these first few hours and days of admission (Keeble et al 2019); therefore understanding what is happening for the person in the AMU is important.

Nygård (2006) recognised that whilst difficulties may be apparent in lengthy conversations, people with dementia may be very competent in shorter interactions, and that when interviews and observations are combined, and performed in a natural context, the comments made and actions executed will be more closely connected to the experience. Integral to this study was that the narratives were recorded in the context of the AMU.

Although this study focuses in shorter interactions, these are not insignificant. By necessity drawn from the macro mobility of the AMU, most of the many interactions that a person with dementia experiences are short and fleeting. However, even fleeting and fragmented narratives can contribute to the performance of identity in everyday interactions (Bamberg 2004) and can thus help to maintain personhood. Due to problems with memory and recall, there is a 'present-ness' of people living with dementia, and therefore focusing on the narratives of the moment, and not looking for coherency, authenticity and consistency is highly appropriate (Bamberg 2004, 2011). This is important in the context of this study, as all the attributes of these shorter narratives run counter to the biomedical form of narrative that I am railing against.

This study did not seek to elicit long narratives through using pre conceived topics and questions, but relied on spontaneously produced conversations that were accepted unconditionally for what they were – short stories relevant to one moment in time. The fact that the narratives were collected in the AMU was important, as this enabled people to react to the context and mobility around them. And as the data revealed, people reacted in a range of different ways.

As this type of research is new to this environment it can be considered as exploratory, and discovered elements that were not readily expressed, or even experienced, at a conscious level. Utilising a lens of mobility brought into focus the importance of micro-movements of the person, and the macro movements of the hospital ward that surrounds them. Through this study, I discovered that narrative scaffolding involves the acknowledgment of movement, as well as words.

Importantly, through using the lens of social citizenship, this research considers the person not only as a recipient of care, but as a person in their own right who is struggling to establish meaning and hold onto their personhood, in a chaotic and unfamiliar environment. Therefore this study is not an exploration of the experiences of care per se; but an exploration of the person as an individual, and social, being.

However, despite aiming to be open minded during data collection, and record what I saw and heard, it was still difficult to place my personal narrative of collecting data for a thesis to one side. Talking with Ivy brought recognition of the fact that I moved the conversation on (towards my narrative) because I felt uncomfortable about Ivy's revelations of the man exposing himself to her when she was a child. Albert showed just how easily a person can be thrown from a position of comfort by an ill judged question. Covertly, and sometimes overtly, I was looking for a story about what it was like to have dementia whilst being an inpatient on an AMU. It was almost impossible to not look for my narrative and to remain open.

Noticing the embodied narratives that are considered in this thesis showed that connecting with people with dementia does not have to rest solely upon the transfer of verbal information, and that focusing on interactive abilities provides important ways to enhance social connections (Kindell et al 2017). Consider Rose and her micro quest for a cup to tea and a tissue. Does Rose's lack of words denote a lack of her comprehension? Or does my use of words denote a lack of my comprehension? Who is forefronted? In the biomedical narrative the interaction is in the control of the health professional; as is the length of the interaction, the subject matter, the manner of its closing and the interpretation of its content (Killick and Allan 2001). Viewing Rose through a biomedical lens disempowers her, and ignores the fact that people living with dementia can use a wide range of communicative skills that vary with time and context; and require real-time

awareness, assessment and adaptation by the health-care professional (Harwood et al 2018). Recognition of a person's narrative citizenship changes dementia from being an individual property, to that which requires scaffolding from those around.

### 8.4.1 Reflections on the method

Collection of data was a simple construct. I asked the person if they would like to spend some time with me, and if they did, recorded what happened next. I endeavoured (not always successfully) to only ask questions if they were contextual to the words and kept the person in their story; and if words were not used I sat quietly and used touch and gaze to communicate. What I used was a different language to the medical one, and to a lesser extent different from the language of research; I avoided direct questioning and attempted to put my own search for narrative in the background. I did not frame the interaction around the necessity of getting my questions answered. I found that to exist only within the framework of another's story when that story leaps and swerves in time and place is not easy. The search for coherency in a narrative is hard to ignore.

As qualitative researchers we know a certain amount about avoiding chronological questions with people who have dementia (Digby et al 2016), however, potentially *any* question is stressful. The stress the question causes can be seen in their movements as well as their words, such as when Albert searches for the name of a fish. Consider the narrative effort involved for a person with cognitive disability to participate in a non-structured interview, or to answer the ceaseless biomedical questioning that is inherent to a hospital admission.

Focusing on conversational storytelling helped to bring into focus the fact that this is a joint activity that requires varying degrees of collaboration, scaffolding, repair and disentanglement (Hydén 2018). This study also sheds light on just how difficult it is to achieve these with an unknown conversational partner, or when the partner is under considerable stress themselves. This all has to occur within the noise and movement of the AMU. When scaffolding does happen well, it is with a sensitive and patient conversational partner who know the person with dementia well, as with Ivy and her daughter. For those of us who do not know the person with dementia well, sensitivity to their movements and micro movements can help to indicate whether our scaffolding is successful or not.

Narratives of people with dementia have been critiqued as containing paradox and contradiction, lacking in consistency, being vague and non-committal (Phinney et al 2007) because the listener has focused on finding meaning only from the words. Consequently, as discussed in Chapter 2, researchers have considered people with moderate and severe dementia too difficult to interview

and have excluded people on the basis of standardised cognitive tests; or other people such as carers and relatives have spoken for them. This has profound consequences both for the theoretical conception of what a narrative is and for the ways narratives are analysed (Hydén 2018). When we are only looking for our narrative, there is a risk that the person inside their own story becomes invisible.

#### **8.4.2 Video**

Part of the ethos behind utilising video in this study was to enable people with dementia to take a more active role in the creation of data. Claims have been made that participatory videos made with and by people who have dementia can empower people to tell their own stories and enable other people to listen to them (Alsawy et al 2019; Capstick et al 2016; Capstick 20012, 2011, 2009). This concept of the empowerment of participant videos is not universally accepted, as some argue that their use can be considered as burdensome, or a cause of fatigue, irritation and discomfort (Muir and Mason 2012). Additionally, when videos are elicited by researchers there is an underlying assumption that the participant has similar interests to that of the researchers (Muir and Mason 2012), and that the researcher is not only searching for their narrative.

To enable active participation in data creation, each participant in this study was asked if they would like to use the video themselves, and if they would like to view the completed videos. Jane was the only person who took up my offer of using the tablet and chose to video me. However, it quickly became apparent that although I handed her the tablet as it was recording, she could not cope with the controls and kept touching the pause button, resulting in only a few seconds of content. Thus my initial aim to have an element of active co creation with the participants was not met. However, Capstick (2012) argues against the stance that active participation is an essential component of participatory research, and that participants should operate the equipment for themselves and in the process learn how to use it; instead she argues for making adaptations to the process so that each participant should be enabled to engage at a level at which they are comfortable.

Feedback from people about their videos also did not occur in the way that I had anticipated. Roger did not wish to review his, neither did Philip or Bert. In common with Hung et al's (2017) findings from their go-along interviews when videos were played back to patient participants, those participants who did comment, made comments about their appearance in the film, rather than the content of the data. Rose looked at her video and asked "Who's that?" and then "Oh I look old, I'm 94". Followed by "I look anxious" and "there's a bruise on my face" and then after some consideration "yes, that's me". Ivy enjoyed looking at the video, but commented mainly on

her appearance. She did not at first recognise her daughter and was concerned about a shadow on her face “I’ve got a moustache”. I realised later that she had macular degeneration. Jane watched part of her video and apologised for telling me that I looked old. My expectations that people would provide a deeper layer of insight into their videos were not met.

However, I believe that I was fore fronting my narrative, that of the researcher looking for data. Videos are not a simple visual representation of reality, they are taken through a lens by a person with an agenda – they want to record something, in this case a conversation. It is therefore necessary to work reflexively and to also document significant contextual information, analysis of the making of the video and inclusion of the participant’s reaction to the film (Pauwells 2010). Contextual information was recorded as field notes, and also captured by the video as the surrounding soundscape. These added depth to the data and contributed significantly during the analysis.

The participants were much less concerned about using a tablet, making their own video, or reviewing their video than I was. They settled for a level of participation that they found suitable. It was only during analysis of the data that it also occurred to me that the contents of the videos could be potentially upsetting or harmful. People do not look their best when they are in hospital due to an acute illness or social crisis, and viewing oneself in this situation, especially if you have visual signs such as Rose’s facial bruising, can be upsetting.

Video based research that is well designed can yield significant benefits by improving the understanding of healthcare and enhancing communication (Parry et al 2016), but it also needs to be noted that videos can only provide glimpses and these are sometimes quite profound, but usually quite eclectic and always partial (Muir and Mason 2012). The videos that were collected for this study could be considered to illustrate all three of these elements.

This study included an eclectic collection of videos that revealed more to these narratives than that which could be conveyed by the words alone. The narratives showed that conversational storytelling is a multimodal event and this needs to be reflected in the methodology (Hydén 2013) when recording them. The use of videos in this study was able to reveal the layers of meaning that could be established when both words and movements were considered – it enabled the visual consideration of embodied selfhood and how this can be displayed; yet it is important to recognise that these videos portrayed only a tiny fragment of a person’s inpatient stay. They illustrated only one specific moment in time.

The use of video in an AMU necessitated taking an element of risk, as video studies have not been previously undertaken in this setting. However, no opposition was met from healthcare staff, in

fact the opposite. On each occasion that I visited the ward, staff went out of their way to help me to recruit participants, and engaged enthusiastically with me in discussions around capacity and consent. Thus the actual process of data collection led to an unexpected chance to undertake learning opportunities with healthcare staff. Patients also appeared to find using the tablet a welcome distraction, and viewing pictures and video of my family enabled me to be open about who I was, and what I was doing. However, this in itself raised some issues that I discuss in the next section. The use of a tablet was unobtrusive, and pulling the curtain between the participant and the next cubicle protected the privacy of other patients.

I have shown in the previous chapter how this noise and movement of people and equipment impacts on the narratives of people who have dementia, and particularly how this is shown through movements and micro movements. I have utilised some of these videos at conferences and in teaching sessions. They have highlighted to the audience the volume of noise and disruption, and how frustrating it is not to be able to hear what is being said, as the words of some participants are all but drowned out.

## **8.5 Ethical debates and dilemmas**

This section considers matters of capacity, consent and inclusion. This study has at its heart the process of consent and how this applies to people who have a diagnosis of dementia. The Mental Capacity Act (2005) is central to the ethical foundation of the study. The Act states that “a person must be assumed to have capacity unless it is established that he lacks capacity”, and capacity must be assessed in terms of a person’s ability to make a specific decision at the point at which it is required.

On deeper reflection I started to understand that there are also ethical and moral risks stemming from the exclusion of people from certain types of activities and from research; and from exclusion from the dialogues and rhetoric that shape their care. This study uses situated ethics to take the stance that until proved otherwise, a person is able to consent to taking part in a videoed conversation, and to decide if the data should be used for research and education, even if that person has moderate or severe dementia. Molyneux and Geissler (2008) argue that situated ethics considers the relevance and application of ethical principles for different studies and contexts, and should take into account the realities of complex individual and institutional imbalances in power. More specifically, inclusion into this research was not to be denoted by a single assessment of capacity and a signed consent form, or by the use of a formal cognitive assessment tool.

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My first video conversation was with Elizabeth. She was approached by a therapy assistant who had identified her as someone “who likes to chat” and they discussed the summary information sheet together. Elizabeth wanted to hear more about my research so I went over and explained it using the contents of the participant information sheet as a guide; and I showed her a video of my mother to give the conversation context. Elizabeth agreed to take part. Hospital policy is that if a person is to be photographed or videoed they must sign a hospital form (Appendix G), Elizabeth was happy to do so, and a copy was placed in her notes.

After the recording was finished, I replayed some of it, and we talked about how this would be used in my research, and that it could be shown to a wider audience for education purposes. Elizabeth was happy to consent to this use, and at this time clearly understood what she was agreeing to.

Roger was initially approached in the same way as Elizabeth. He also agreed to take part in a video, and was happy to be seen in bed in his pyjamas. He understood that I was a researcher and that I was collecting stories from people like him who have dementia. He did not wish to review his videos but was explicit in that he wanted his point of view to be heard.

On reflection, Roger illustrates several of the issues that I have found difficult to resolve as I have undertaken this study. Roger was angry, frustrated and wanting to go home. He wanted his point of view heard, and understood the use of his video for education as well as research. He understood that I was not a clinician: *“and you listening to this as a non-medical person how could you possible say that I am er suffering from dementia?”*

However, as I re read this I feel uncomfortable. My protocol stated that in order to prevent people from feeling coerced to participate due to the clinician-patient power imbalance, I would distinguish myself from clinical staff by not wearing a uniform and displaying a badge that said “Researcher”. This clearly worked with Roger, but I was left feeling that I had somehow deceived him; I AM a clinician, but not working as one in that moment. Did this mean that I was lying to Roger? Roger was honest with me, I felt that I was not honest with him. Should I have made it clear to my participants that I am a clinician doing research? Would this have created a different relationship or power dynamic?

Whereas the clinician as researcher role has been considered in the health literature (Hey-Smith et al 2016; Lawlor 2003), the issue of deception does not appear to have been discussed. Consideration of the clinician-researcher role has focused on the clinician “adopting a stance that alters relational and interpersonal processes familiar to the clinical arena” by consciously not performing their role of clinician whilst collecting data (Lawlor 2003). This adoption of a neutral

stance aims to enable a non-clinical lens to be applied to observations and data collection (Lawlor 2003). Concerns for clinician-researchers also include such issues as how the researcher should deal with clinical queries or revelations, whether to give hands on help to clinical colleagues, and whether the participant will hold back information (Hey-Smith et al 2016). Following their systematic review, Hey-Smith and colleagues concluded that clinician-researchers cannot adopt a wholly non-clinical research identity and this was mirrored by my experiences. It was exceptionally difficult to not view my participants through a clinical lens, particularly as I read their medical notes prior to meeting them; thus I was already primed cognitively as a clinician.

The clinician-researcher narrative is firmly focused on the researcher and not on the effect of the clinician-researcher on the participant. Again, I think back to whose narrative is being told, and in the clinician-researcher literature, it is not that of the participant. I have found that when a non-clinical research identity is adopted in such a way that the participant accepts the researcher as simply that, a researcher, this is not always comfortable. Is this yet another way that people are disempowered by the hospital environment?

Roger also highlights another ethical issue. In the time that we spent together Roger was angry and frustrated. He consented to the use of his data. But as time has passed I wonder if Roger would still want his video to be shown. Similarly for Elizabeth who was clear about wanting to help with research and education, but was ill and tired. Consenting to the use of a video has consequences that reach far into the future. They might feel differently today. I am conflicted. If a person who does not have a dementia diagnosis agrees to take part in one of the networked TV shows that are now regularly made within NHS hospitals, the film would be widely available even if, at some point in the future the person regretted their decision to take part. In reality, no participants are immune to the potential problem that at some point in the future they may regret having given consent, and it is therefore vital that clips are chosen with great care, and are considered by the researcher to be non-controversial and unlikely to become a cause of regret for those involved (Muir and Mason 2012).

Even with this in mind I still feel concerned. I have to also consider that Roger and Elizabeth have a dementia diagnosis and as I re watch the videos and show them for educational purposes, I worry that they might have changed their minds. So I question why I feel differently about these decisions, and conclude that it is my problem and not theirs. Aversion to causing harm to participants with disability is tied to notions of vulnerability assigned to their identity, and can manifest in paternalism and over-protection, assigning them to a position of increased powerlessness (Shakespeare 2015).

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I am uncomfortable because Roger and Elizabeth have been empowered to make their own decisions, decisions that have future consequences. To deny someone the ability to make decisions for themselves further disempowers them. It is for me to use ethical and moral considerations around when and why I show these videos, because in making their decisions, Roger and Elizabeth have trusted me with the consequences.

My discomfort at using an enabling consent process is further indicated in the following field notes:

*Jane is another really interesting consent example. She definitely understood the video and was keen to chat and video us, although she struggled with the technology. I am sure that she understood that this was research; I discussed my project and kept reminding her that I was from the university. She was clear on two occasions about a wider audience – not for them. I am happy with these decisions; I believe that I did not infantilise Jane's decision making capacity. And yet I still have a level of discomfort around "allowing" a person to make decisions for themselves. I am steeped in the has/has not got capacity world of clinical decisions.*

Again, in academic discussions around the clinician-researcher dual role, considerations of discomfort of the researcher when empowering a "patient" are not discussed. Is this because by using the concepts of capacity and consent we become used to our participants being disempowered. When does protection from harm become another form of coercive control?

In practical terms this discomfort reflects the power imbalance in the assessment of capacity, and the accepted power imbalance that is present in all clinical encounters. When power is taken away from the clinician-researcher it is not comfortable, leading to the reflection that the mental capacity act, by deeming some people to lack capacity appears to be used as another tool of disempowerment.

### **8.6 Critical lens and translation into practice**

The act of truly receiving another's story, according to Charon (2005), can be considered as three movements. The first movement is attention, the second representation and the third affiliation. This thesis has brought attention to the importance of movement, attempted to represent these movements in order to understand the teller; and through attention and representation aimed to establish an affiliation with the narrator and understand their personhood. The fore fronting of movement as a fundamental aspect of understanding a person with dementia in an AMU, has I hope been illustrated by the data.

Attention to the narratives that are discussed here challenges the view that the experience of disability stems from the individual as opposed to society (Bartlett and O'Connor 2010). Noise produced by people, clanking trolleys, floor cleaning machines and different activities make the environment very disabling (Marshall 1997) both physically and cognitively. Ward changes and short and multiple interactions all disempower and disable a person when they become a patient. Add to this the discouragement of moving around or leaving the bed space, and this disempowerment can result in physical harm in the form of decreased independence and mobility. The consideration of individual narratives can help to build a collective understanding of the effects of the context of care, and how movement, either too much, or too little, can be another form of malignant social psychology (Kitwood 1997).

Shifting the lens away from that which considers the carer/cared for dyad and towards a lens that considered mobility, changed the focus of attention. This altered focus on the narratives revealed not a passive, immobile recipient of care, but rather a person actively maintaining a sense of personhood. We have been looking so hard for our narratives around care processes that we have missed seeing the narrative citizenship of the person.

All the participants had a story to tell; my expectation initially had been that people would talk of the reason that they were in hospital or of their dementia. Yet, apart from Roger the participants did not talk of these. On consideration, these “non-narrated” (Vindrola-Padros and Johnson 2014) factors of the stories were part of my assumptions of what to expect from a hospital narrative; my biomedical lens was fore fronted, preventing me from seeing and hearing the story as it was actually told. Fore fronting the narrative citizenship of each participant enabled me to see the person in front of me as they were in that moment in time.

As I have worked through the process of this thesis, it has become clearer and clearer to me that the process, the *act*, of listening is a skill that we do not get taught yet is at the heart of every encounter. We talk of “unconditional listening” where we aim to be un-judgemental in our reception of the story, but how is this achieved in practice? Even being cognisant to my narrative has not stopped it being at the forefront of my mind in many interactions as I noted after videoing Bert:

*After Bert's video I feel despair. What am I getting? Is there any value in what I am doing? My mind keeps going back to “mobility” and “risk”. How am I going to address these issues? Is my data worthless?*

And this sums up the issue. I am a researcher and I am searching for *my narrative*. Despite my assertion that I wanted to “create data” with my participants and listen unconditionally, like all

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researchers I had an agenda. I was looking for a particular story, that which would tell me “what is it like for you”. As such I was missing the fine details that revealed something of what was happening for a person when acutely unwell, and in a strange place. By looking for my narrative I was not allowing space to understand theirs.

Charon (2005), a proponent of narrative based medicine considered the need for rigorous and disciplined training in reading and writing for healthcare practitioners, for the sake of their practice. Although here I am considering listening to narratives, Charon’s principles still apply. These are the need for attentive listening, simultaneously being transported by a verbal story whilst critically analysing, adopting another’s perspective, following a narrative and being curious about other people’s motives and experiences, and tolerating the uncertainty of stories. These are not easy things to do in a time orientated and busy clinical world, and as this thesis shows, much of the “telling” for people with dementia is in the form of movement and micro movement – the embodied language.

Moreover, coming to a point of affiliation with the person’s embodied language led me to an encounter with myself – I started to understand that I too am an integral part of the encounter, and as such have an effect on the story. This has led to the question of how would each interaction be different if the conversational partner was different?

To a certain extent this is answered in the data. There are three types of conversational partner: me, the researcher/clinician who is a stranger; the calm and relaxed daughter of Ivy; and Philip’s exhausted and worried wife. This narrative enquiry is not aiming to draw generalisation across all the stories, but these types of conversational partner do shed light on how and why some interactions are different to others.

When a person with dementia is in a place where they have to work hard to maintain a sense of self and make meaning from their surroundings, the things that make a difference are small and subtle. Ivy lay in bed; beside her sat her daughter Eileen, who said little but used eye contact, eye movements and touch to support her mother. Ivy was able to recount her story until I threw her off course with my ill-considered questions. But with Eileen beside her, she was soon back on course. Philip’s wife and I outpaced him in our conversation and he was effectively excluded. This did not pass unnoticed by Philip in either his words or his embodied language.

Then there was me, the stranger. I have considerable experience working with people who have dementia, but I have less experience of socialising with people who have dementia. Additionally, I was looking for my story as a researcher, and the effects of my ill-judged questions were apparent in the data. People with dementia are disempowered and one way in which they are

disadvantaged in relationships is through losing control over how interactions and communication arise and unfold (Killick and Allan 2001). Eileen expertly showed how a 101 year old lady with dementia and an overly delirium can be supported, even in an AMU, to successfully tell a story and maintain a sense of self.

There is a developing recognition of the significance of embodied language in dementia studies, and increasing efforts to expand understandings of dementia by incorporating the body and theorizing its interrelationship with the larger social order (Kontos and Martin 2013). This emerging subfield of dementia studies puts the body and embodied practices at the centre of explorations of how dementia is experienced (Kontos and Martin 2013). Kontos (2005) argues that bodily sources of agency which are grounded in the pre-reflective level of experience are fundamental to the manifestation of personhood. However, this study has demonstrated that sensitivity to embodied language does not come naturally.

Movements of people with dementia have generally not been considered as manifesting personhood. Movements in hospitals are associated with functional tasks, falling over, repetitive walking or disruptive behaviour. Body/mind and body/self have therefore been constructed as distinct and separate entities in dementia and dementia care (Kontos 2005). Consideration of the body as a way that experiences and a sense of self can be understood and conveyed is not well explored in the methodological literature.

Chadwick (2017) discusses how to do “fleshier” research through a consideration of women’s experience of birth. She found that there appeared to be no fully-formed language or vocabulary with which to speak about the fleshy, emotional, intensely embodied experience of giving birth. Whilst Chadwick considered the emotions and feelings that could be conveyed through the way that the words were spoken, transcribed and presented, she did only consider the words. She did not capture images of the women’s bodies as they experienced birth and so was unable to capture their truly embodied language.

A focus on embodied language helps to address the conflict between the biomedical narrative and the narrative of the individual with dementia. People are not telling the stories that they ought to tell about their illness. “Institutional medicine is asserting its preferred narrative” (Frank 1995 p79) and not taking into account the stories that real people tell about their illnesses. People become narratively dispossessed. The health professional and the patient are speaking in different languages and neither appears to have the language of the other, and interpreters are missing. Medical language is a valuable tool, but it is not the only tool; “our insides and our outsides are connected. We cannot tell our stories without telling the tale of our bodies and those who have touched us” (Charon et al 2017 p106). If we are to move forward in developing

innovative dementia care practices, we must develop a new paradigm that respects individuals as embodied beings, deserving of dignity and worth. We need to learn to recognise and respond positively to different narratives of illness.

There is therefore an imperative to maintain and recognise a person's narrative citizenship, so that the ability and opportunity to construct one's own narrative is supported; and the contribution one makes to the narratives of others is recognised (Baldwin 2005). People with dementia on an AMU are not simply a body to be cared for, but narrative agents who contribute to the entire social structure of the AMU. Our institutions are human creations, not objects independent of those of us within them. In rendering tacit knowledge explicit, silenced discourse can speak, thereby engaging questions of power (Yanow and Schwartz-Shea 2016). The AMU would not exist without the presence of people like Roger, David, Rose and Ivy, and their places within it should be acknowledged.

### **8.7 Summary**

This study makes an original contribution to the empirical and methodological research literature by attempting to bring embodied language into sight in the AMU, and in doing so, making the theoretical tangible. The findings from this study have been considered from the perspectives of both a clinician and a researcher.

These stories can be considered as manifestations of narrative citizenship whereby acknowledgement of both the spoken and unspoken stories enables the person with dementia to be understood for who they are in that moment of time. Attention to these narratives changes the focus of personhood in dementia as being a property of the individual, to that which requires sensitive scaffolding by those around. An understanding of movement and micro movement acknowledges that personhood, and the maintenance of personhood, are mobile processes that are fragile and need support.

Close attention to the narratives that each participant shared revealed layers of meaning that included not just the words, but the importance of the movements and the micro movements of each individual. Allowing the body an agential role enables a reconsideration of the clinical relationship with people who use language differently, and shows how by embracing the significance of movement as communication, personhood can potentially be supported.

A wider conceptualisation of narrative can enable the inclusion of people in research who may not be able to articulate their meaning clearly through words alone. This study showed that the use of video to explore these embodied narratives was acceptable to both participants and

clinicians, and that utilising a mobilities lens brought useful insights into the understanding of each narrative and the context of the AMU.

This study also brought into view the discomfort that can be felt by a clinician/researcher when the participant is unaware of the researcher's clinical background. It also considered the power imbalances inherent within the research process when a person with dementia is involved as a participant.

The narratives also show the amount of work that we require people with dementia to do when they become patients and enter our narrative structure. They are in a different place and their identity has been changed by those around them to a patient. Yet my participants clearly showed themselves to be wives, sons, naval men and shipwrights. Facial expressions and body movements, when attended to, demonstrate the amount of work that is required to maintain a sense of self in the setting of an AMU.

Additionally, this research has highlighted the level of skill that clinical and care staff require to keep people with them, or keep people where they are, within their narratives. The occasional misstep and the whole interaction can be thrown into disarray. It is not enough to consider that understanding another's narrative is an intuitive skill. To support and understand the narrative of a person with dementia, and thus support their personhood, requires training in communication skills that is not currently widely available. People in caring roles need to be trained to collaborate, scaffold and repair narratives.

This study has explored the narratives that were shared by people with moderate and severe dementia whilst they were inpatients on an AMU; has found that a mobilities lens is useful in the interpretation of these narratives and has shown that people with dementia can be enabled to contribute to the research agenda in acute hospitals.



## Chapter 9 Reflections on a narrative enquiry

This thesis is a narrative enquiry, and as such the thesis is itself also a narrative. This chapter reflects on my place in the narrative, and how the process of undertaking a Clinical Doctoral Fellowship has affected me both academically, professionally and personally. During the 4 years of this fellowship I also had the opportunity for further clinical and academic development and some of the activities that I have undertaken are shown in Appendix H.

### 9.1 The journey to constructionism

I was a positivist. I have a science degree and a physiotherapy degree which both included rigorous attention to positivism; in this world the randomised controlled trial is the gold standard against which all else is judged. During the first part of my clinical career this paradigm seemed highly appropriate: evidence was evaluated against criteria, outcome measures were used that could quantify the effect that my input had on a patient; new ways of working were implemented in the areas where I worked that had clearly taken into account current quantitative evidence.

But as time passed I began to puzzle over why it was believed that a simple outcome, such as the time it takes for a person to walk a set distance, could distil down into one number the complex treatment that takes place in a complicated environment. I began to question what it was that I was doing, and how what I was doing could be evaluated. I realised that some things that I was doing could not be measured with numbers. Knowing that what I was doing must, in some way, be open to “measuring” I undertook a masters module in Outcome Measures. Although this strengthened my ability to critically evaluate quantitative research, it left me badly disappointed. I still could not measure how my physiotherapy input was effecting my patients and clients in everyday practice. I could see quantitative measures in use all around me, but I had a growing suspicion that they were not telling me anything useful.

And then I did a module in qualitative research and it felt as if the lid had come off Pandora’s Box. I suddenly realised that the complexities of people and healthcare settings could be looked at in an entirely different way. That purely counting what went in and what came out was far too simplistic and, how obvious it seems now, did not take into account the most important pieces of the puzzle – the players in the scene.

This growing realisation did not just affect my professional perspective. I began to see the fluidity of people’s ideas and actions. I saw how the story telling and rhetoric from the government and the media are able to influence behaviours at an individual and national level; I started to listen

## Chapter 9

carefully, not only to what was said, but how things were said. I realised that the way that we act is shaped by what is around us and the way that other people behave towards us. It dawned on me that the society I live in does not have a fixed and scientific shape but is created by the opinions, behaviours and beliefs of the people within it. That these opinions, behaviours and beliefs can be altered and manipulated. I stood back and looked at familiar things. I started to see the hospital as a social system that has been created by those of us within it and I started to question the way that we worked; the way that people become patients and the power imbalances that are produced by the very act of walking through the main entrance. I began to realise that reality is constructed uniquely by each individual and that truth is not absolute.

My evolution into a constructionist had begun.

This was not a quick process. I still had to fend off my positivist foundations where I was thinking about triangulation in terms of getting to the real truth, but constructionism tells me that this is impossible. That all I am seeing is the construction of the social phenomenon at that point in time. And I really like this because if I have a really poor short term memory, then my reality is constructed in that moment. What happens before and after is not significant to me at that moment; and I wonder, is it that people with dementia are able to experience the “real” world in that it exists only in that moment and that context?

My narrative turn occurred whilst at the dementia summer school in Sweden in 2016. I was fortunate to attend a seminar with Lars-Christer Hydén. He articulated what I was observing in clinical practice but that I had no framework from which to understand – that people who have dementia tell stories that are non-linear, non-contextual but clearly meaningful to the narrator. He recognised the generally held assumption that narratives are temporal and include a beginning, middle and end; and discussed the question of whether the inability to tell stories about the past and to establish a plot implies a loss of identity.

I began to get interested in how people construct their reality and if this reality can be understood by those on the outside. I started to observe people communicating whilst I went about my clinical work; became fascinated by the different forms of communication that are used, and the stories that I heard and saw. People were clearly telling a story: Alfie who had a bed on the unit which was next to a busy thoroughfare was in Johannesburg airport and anxious that he would miss his flight; Fred was highly anxious and upset because he couldn't find his little brother with learning difficulties who he was always tasked to "look out for"; Ben was also anxious as he was trying hard to get up and walk because he was going to miss the coach. Edith said that it's bewildering and there's too much going on.... Brian talked of the noise of shoes on the hard floors "the clacking, the clacking its driving me mad". And Alice who took one look at me and

threw her water jug. Something is clearly imperative and contextual to the people that I have met, but is not temporal or contextual to those around them. The people that I met clearly had important things to say. It seemed to me that the problem was that the listener was not equipped to understand their stories.

## 9.2 Questioning the process of consent

The moral dilemmas posed by inclusion, exclusion and capacity to consent (or not) have become increasingly imperative to me as I have reconsidered my research, clinical and personal worlds in the dawning light of citizenship (Bartlett and O'Connor 2010). This has led me to question labels that are commonly applied such as the term "capacity". What does it do to rights and empowerment when you are labelled as lacking this attribute? Why have the terms capacity and lacking capacity been used so widely in research, and who should be in a position to judge? Why is the ability to demonstrate agency and decision making denied to certain people? These questions were at the forefront of my thinking when applying for ethical permission to undertake this study.

Getting through ethics felt like an enormous achievement because it meant that the committee had listened to my argument that utilising such complex participant information sheets and consent forms was effectively excluding many people from the research process. It also validated my idea of the two part consent process; so many people with dementia are completely able to say whether they want to join in a conversation; not so many are able to understand research and education.

## 9.3 Lessons along the way

In planning my research I was fortunate to meet Veronica and Christopher Devas who are dementia advocates, at an Alzheimer's Society Legacy event and taught me so much about what it is really like to be a couple dealing with dementia. I trialled my idea of using the tablet to video people with them to see if it was an acceptable approach.

They are a beautiful couple in their 70's. Christopher has severe dementia and speaks very little but clearly engages in the socialness of the moment. Momentarily he would light up, like when I showed him a picture of his boat (we had been talking about sailing), and start to talk and point at parts of the boat, make eye contact with me. When their cat sat on his lap, he suddenly started to talk fluently, he stroked and talked to her, smiled and laughed. They are activists and adventurers – witness "Vera" the van outside. Bought so that they could visit distant friends (they are clearly very sociable) and yet Christopher can still be in a familiar environment. When Veronica talked

about continence, grumpy mornings, doing all personal care it astounds me that she can still also travel in a van and keep up with life and friends. Veronica calls dementia the “robber disease” – it steals parts away.

Strength is the word that I thought of after leaving them.

Veronica lent me their DVD of the Grayson Perry exploration of modern families and his making of the vase to represent Christopher and Veronica. He explores identity and how it is co-maintained when one person has dementia and valued memories and experiences are lost to one person. The video shows how Christopher mirrors Veronica’s mood and social cues. However, when Christopher is shown on the boat on Poole Harbour he is animated and articulate – what I imagine is the old Christopher is fleetingly present. I know that Veronica still takes Christopher to disability sailing, but it is very hard work for her.

#### **9.4 The anxiety of data collecting**

Having planned and talked about my research for so long, and feeling that I had the expectations of people who I respect and like to live up to, I found myself frozen with anxiety. Will people feel coerced to participate? Will I be revealed as a fraud? My clinical uniform is a type of disguise that allows me into a certain world and protects and separates the real me from the hospital. Who is the “me” in this research context? Who am I in relation to the community I am researching within? Insider, outsider, expert?

My first understanding of collecting data therefore became the acknowledgement that reflexivity involves an immediate, continuing, dynamic and subjective self-awareness (Finlay 2002). There are multiple tangled components of the clinician/researcher/participant triad that impact on me during all encounters. My colleagues have only known me as a clinician so my first disentanglement was to arrive in my own clothes and introduce myself as being in my “researcher role”. I felt exposed and vulnerable having not realised how much of a shield it is to wear a uniform and have a clearly understood role within the defined hierarchy of the unit.

Prior to starting data collection I had already started to reflect on how I talk, react and connect with people when they have dementia. This started when I visited the AMU with my 13 year old daughter on one occasion to collect a book from a friend. My daughter and I got chatting to a lady sitting at the nurses’ station who had dementia, and I was deeply shocked afterwards when Jessica told me that she thought my tone of voice was patronising. On reflection I thought that this might have been due to a perceived (on my part) power imbalance. I started to watch more closely how I interact with people and how I felt during these interactions. At the unveiling of

portraits of people living with dementia “Inspirational Voices”, a place where I was neither clinical or researcher, I recognised that I was talking differently, I was aware of feeling uncomfortable at times and at other times I felt that a connection was made and I felt comfortable and could be “myself”. I was not sure why this was the case.

Kreiger (1996) writing about collecting ethnographic data, noted that there was much that she could not uncover or analyse because the content fell beyond her limited experiences. She recognised that her “task was to try to uncover what I could with the tool of myself and my personal recognitions [.....] if the understanding of self is limited and unyielding to change, the understanding of the other is as well”. I needed to locate and acknowledge myself within the context of the data collecting activity in order that I could start to make sense of what I was hearing, seeing and doing. This entailed an acknowledgement, for example, of when I feel uncomfortable and disconnected, or when my personal narrative became fore fronted.

Therefore, on my first visit to the AMU I consciously decided not to try and collect patient videos or narratives, but instead to observe, listen and watch the life on the unit. To stand apart from my clinical and researcher role; I tried to see the unit as it was when I first started work there – noisy, chaotic, full of strange smells and multiple people moving around. I questioned who I was as I stood there, feeling slightly anxious and out of place.

As I had arrived at lunchtime I sat with Annie and helped her with her meal; we talked about her, about her dementia, and I told her about my research. I was struck by how different it was to have time to listen, and to not feel under time pressure as Annie very slowly ate her pasta and drank water. There was a humanity in this interaction that is missing from clinical work. I chatted with two other people with dementia. The ice was broken and on my next trip to AMU as a researcher, I started to collect data.

## 9.5 Learning from the data

Disentangling the clinician from the researcher from the private person was something that I consciously tried to do, yet if I am honest, found impossible.

After the end of the conversation with Roger, I am left speechless, I have no idea what to say to Roger, I turn off the video. I’m a fixer, a clinician, I want him to get home, but we are both powerless inside an organisation that has found problems for Roger. Now that these problems have been found the biomedical system within which we are both situated necessitates that these are addressed before he leaves. I know from his notes that Roger’s daughter is “at the end of her tether”; is this impacting on discharge decisions? I also know that when Roger arrived in A&E he

had a delirium and his notes say “aggressive” and “alcohol abuse”. How much are these labels affecting how clinicians treat Roger? Even sitting here writing I am getting an anxious tightening in my throat and my heart is beating hard; did Roger go home, or is he still in hospital? If so how will he cope?

Watching the video away from the hospital for the first time I felt deep sadness and tears started to well up in my eyes. This surprised me as I have heard stories similar to Roger’s many times over during my clinical work and not been so affected.

Hochschild (1993) recognised that the capacity to deal with people, relationships and feelings in the workplace requires “emotional labour”. Emotional labour is the “silent work of evoking and suppressing feelings – in ourselves and in others” (Hochschild 1993 p333). Clinically emotions are suppressed, firstly because the continual engagement of deep feelings would be exhausting, and secondly because it is not deemed acceptable. The latter was brought home to me in a clinical encounter. I was discussing a patient with a colleague and mentioned that the behaviour of a patient’s relative had made another colleague cry. My colleague responded with “I think she’s a bit flaky really”. As Hochschild recognised, the self-management of emotion entails conscious effort and hard work, and to not be able to manage this work leaves a clinician open to criticism. Emotional labour is a facet of all aspects of nursing work and enables nurses (and other clinicians) to manage feelings which in itself can create emotional dissonance leading to stress and burnout (Delgado et al 2017). In my case, emotional suppression during my clinical work has become so habitual that I am no longer able to notice that it is happening.

This reflection on Roger and my emotions whilst talking to him made me consider the labelling of “aggressive” that had been applied to Roger in his medical notes. A person who is verbally fluent and understands the contextual environment in which they find themselves can utilise emotional labour to modify their reactions. For someone with cognitive problems compounded by an acute illness the relationship between emotional behaviour and the social environment needs to be considered (Bender and Chesterton 1997). Roger had come into the Emergency department as an emergency, was in a loud and busy environment, and was asked multiple questions by many people. This must have been stressful, bewildering and annoying, and Roger’s emotional reaction of “aggression” was not considered as a form of communication but as a form of behaviour. Without the understanding of his emotional world, we cannot fully understand his social behaviour which will appear to be meaningless, or misunderstood (Bender and Chesterton 1997).

## 9.6 Learning to Question

The biggest lesson that I have learned from my PhD is to question. Slowly, without realising it, I am starting to question all that I see. Why do we divide patients up between different healthcare staff? Why do we need doctors, physios, nurses? As each profession evolves through time we take on different parts of each other's roles. Are the roles created for us? Or do the roles help the patient? Is use of the mental capacity act empowering, or disempowering patients with dementia? I question concepts such as these with my colleagues and am not always popular.

I questioned how, within acute hospitals, we are allowing our older people to leave our care worse off physically and cognitively than prior to admission. I wrote a piece in the Chartered Society of Physiotherapy magazine posing the question that as older people are effectively immobilised in hospital, and through this process they lose independence and mobility, should we not, as Physiotherapists take responsibility and question our practice. If this is happening on our watch, when we are the experts in enabling movement, perhaps we should be seriously considering what we are doing. This was met by a furious response from my therapy services manager, and several senior physios refused to speak to me for weeks. I learned that sticking your head above the parapet can be painful.

I have started to question the "them and us" attitude of healthcare staff to patients. Consistently, to anyone who will listen, I have suggested that we eat our lunches and drink drinks with our patients (if each side wants to do so). We know that under nutrition and hydration is a significant problem for older people in hospital, so why don't we eat lunch together, or have a cup of something together, as part of our work?

I listened to Laurie Taylor's "Thinking allowed" on BBC Radio 4 who mirrored the questions that were starting in my mind. Why are older people positioned so problematically by medicine, nursing, the institution, the health service? Are we frightened that we will see our own future in the people before us? Why are some people silenced and not enabled to speak out? Who does the labelling and why?

At the end of this narrative enquiry I am left in a place where I have many more questions than when I started. And I like that.



## Chapter 10 Conclusion

This thesis had as its starting point the assumption that people with dementia have narratives to share, and that using a mobility/immobility lens can lead to an understanding of these narratives because “movement is rarely just movement; it carries with it the burden of meaning” (Cresswell 2006).

The gap that I have addressed in this thesis is the lack of the voices of people with dementia within acute hospital care research; and where their voices have been elicited it is from the standpoint of a recipient of care. By using a methodology that is novel to the AMU environment, I have shown that movement, mobility and micro movement can be re-visualised as communication. An understanding of this form of communication enables an understanding of another’s emotions and personhood, and a “truth” is revealed that words alone can miss. By utilising a mobilities lens I have envisioned personhood as a mobile process and conceptualised the idea of narrative as citizenship. To deny another’s narrative is to effectively deny them citizenship, causing people to become stigmatised and marginalised.

The findings have been both empirical and methodological.

The first research question asked what narratives are shared by a person with moderate or severe dementia when they are on an AMU. I found that people are sharing a wide range of different narratives, but that to understand these narratives it was necessary to look further than simply the meaning of the words that were used; and that this shared meaning required work from both the narrator and myself.

Empirically, the study found that when the narratives are viewed through a lens of mobility, that the embodied language of the person becomes visible. The disempowerment that occurs when narratives are only seen through a biomedical lens that relies predominantly on words is challenged by attending to all the layers of a narrative.

The first layer, the words, showed people who were actively seeking and making sense of their situation, whilst also establishing their personhood. People shared narratives that moved in time and space; which illustrated the work needed to maintain a sense of self and dignity; which told of loss and of being lost, and of frustration. I found that understanding this layer of meaning was assisted by an understanding of narrative scaffolding and narrative typologies. I also showed just how easily a person can be thrown from a position of comfort by an ill judged question.

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The second research question asked if a mobilities lens could help in the understanding of these narratives. This lens proved to be very useful and revealed a further two layers of narrative language.

The second layer of narrative meaning was seen through the use of conscious body movements in the form of gestures. These gestures supported the narrative, but were used mainly when the narrator was comfortable with the topic. These gestures and actions could be adept and at times contrasted to the fragmented words.

The third layer of narrative meaning was found through exploring and interpreting the movements and micro movements that each person unconsciously made whilst sharing their narrative. These movements were the physical symbols of embodied language and revealed that movements do not only support the words but in some cases tell a different story altogether.

Clinically it is apparent that the language that is used by people who have dementia is often not understood, or is misunderstood, making it difficult to understand and support personhood. People with dementia are communicating to those around them and this study has revealed how they are achieving this. For people with dementia poor outcomes from hospital admission are common; this needs to be changed, and one way of achieving this is to sensitise healthcare professionals to forms of communication that are not only words, and to also look behind the superficial meaning of the words that are used. This will require the teaching of a new skill set.

Additionally, understanding personhood as a mobile process that can be supported through sharing a person's narrative moves the person with dementia beyond being a recipient of care, to a citizen in their own rights who should expect to be recognised and treated with equality.

The third research question asked how people with moderate or severe dementia can be enabled to participate in research.

Methodologically this study has added to the body of knowledge around how to include people with dementia in research in acute hospitals. There has been a virtual absence of the voices of people with dementia within acute hospitals and a lack of methods with which to explore these voices. This study has shown the usefulness of a mobility/immobility lens, and re-visualising movement, mobility and micro movement as communication can reveal a "truth" that words alone can miss.

I recognise that scaffolding a person with dementia to tell their narrative is difficult and is best done by a person who knows them well and who is not stressed. I found how unconsciously it was

easy to move the conversation on (towards my narrative) when I felt uncomfortable with the narrative topic.

I used the narratives to challenge the idea that people convey meaning solely through talk, and explore how the body itself is able to convey what is meaningful to that person at that time, and give examples of how this actually happens in reality. John Yorke (2013) in his exploration of storytelling describes this as making sense of the disparate, whereby the disparate is fused, given shape and in doing so instils in us quiet. I am attempting “sense making” from the stories by understanding a language that we know exists, that of embodiment, but which we are unable to translate. And through this, to understand the person in the place and in that moment in time. For after all, are not all encounters with strangers the embodiment of making sense of each other in the moment?

I argued that words should be relied on less to establish “fact” and “truth” and that movements teach us to be more open to other layers of meaning. Movement and micro movements, when considered, enable a deeper understanding of the person; enables the person to be seen; show the work that is done to maintain personhood; and can give indications of emotional state

Leaving the actual, physical body, as well as creative use of language, out of the analysis and understanding of stories becomes especially problematic in research with people who have dementia and whose verbal resources are compromised (Hydén 2018). Baldwin (2005) has argued that to challenge the disabling master narratives of dementia, counter-stories that are individual, enabling and meaningful need to be both constructed and realised. I hope that how this can be done in reality is shown in this thesis.

The potential that the exploration of movements and micro movements has for extending our understanding of the experience of an acute hospitalisation has been raised throughout this thesis.

### **10.1 Limitations and strengths of the study.**

This is a narrative enquiry, and as such the findings are necessarily my interpretations of the narratives that were shared with me. I have used a continuous process of reflexivity throughout this research to consider how my presence effects both the data collected and the analysis. I have also used a theoretically informed analysis in an attempt to produce responsible knowledge.

This study was carried out with a small number of people on one AMU in the south of England, and the findings should be considered as being relevant to this context only. The study was also

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time limited to satisfy the constraints of a doctoral research study, and each narrative encounter was also necessarily time limited due to the pace of the AMU.

However, this study also has strengths. The study has applicability across social processes, and shows how when narratives are reconceptualised and understood, the citizenship of a person with dementia can be upheld by recognising and supporting personhood. People are working hard in a noisy and hypermobile environment to inform healthcare professionals of who they are. If serious attempts are to be made to improve the outcomes of an acute hospitalisation for people with dementia, the power imbalances that are shown through these narratives need to be addressed. This can be done if research studies utilise methods that enable the narratives of people with dementia to be included and heard.

## Appendix A      Reviewing the literature

This thesis draws on a broad literature base and I included any literature that could provide insights into the care of people with dementia in an acute hospital; mobility and independence within acute hospitals; mobility and mobility theories, and narratives in the context of acute medicine. At the heart of this literature exploration was a systematic review that addressed the question “how is mobility and/or independence experienced by a person with dementia in an acute hospital?”

The literature search was conducted using the EBSCO platform to search the databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychINFO and AHMED.

The key search terms and MeSH headings used were as follows: Dementia, Alzheimer’s disease, cognitive impairment, hospital, inpatient, mobility, activities daily living, independence, experience and perception. Citations and references from relevant texts were hand-searched. Searches were combined with the Boolean operators AND/OR. The search terms varied according to the individual database used and the mapping key terms available. All research designs were included.

The literature search was limited to English language papers and reports published between 2001 and June 2018. The searches were re run at the end of 2019 to capture papers published in the preceding eighteen months, and 6 more studies were identified. Searches were restricted to papers published since 2001 as it was felt that these would be able to reflect the current climate of care for older people in modern health care systems. English language papers only were searched as there was no translator available.

In order to ensure that all relevant records were found, the reference lists of significant articles were hand-searched and citations of these articles from Google Scholar were also searched. Leading authors in the field of dementia care research were contacted.

Duplicate references were identified and removed. A staged selection process was then undertaken as follows:

1. Titles of references were reviewed.
2. Abstracts of articles passing the first stage were read.
3. Articles passing the second stage were read in full.

Inclusion criteria:

- Studies of mobility or independence that included people with dementia.

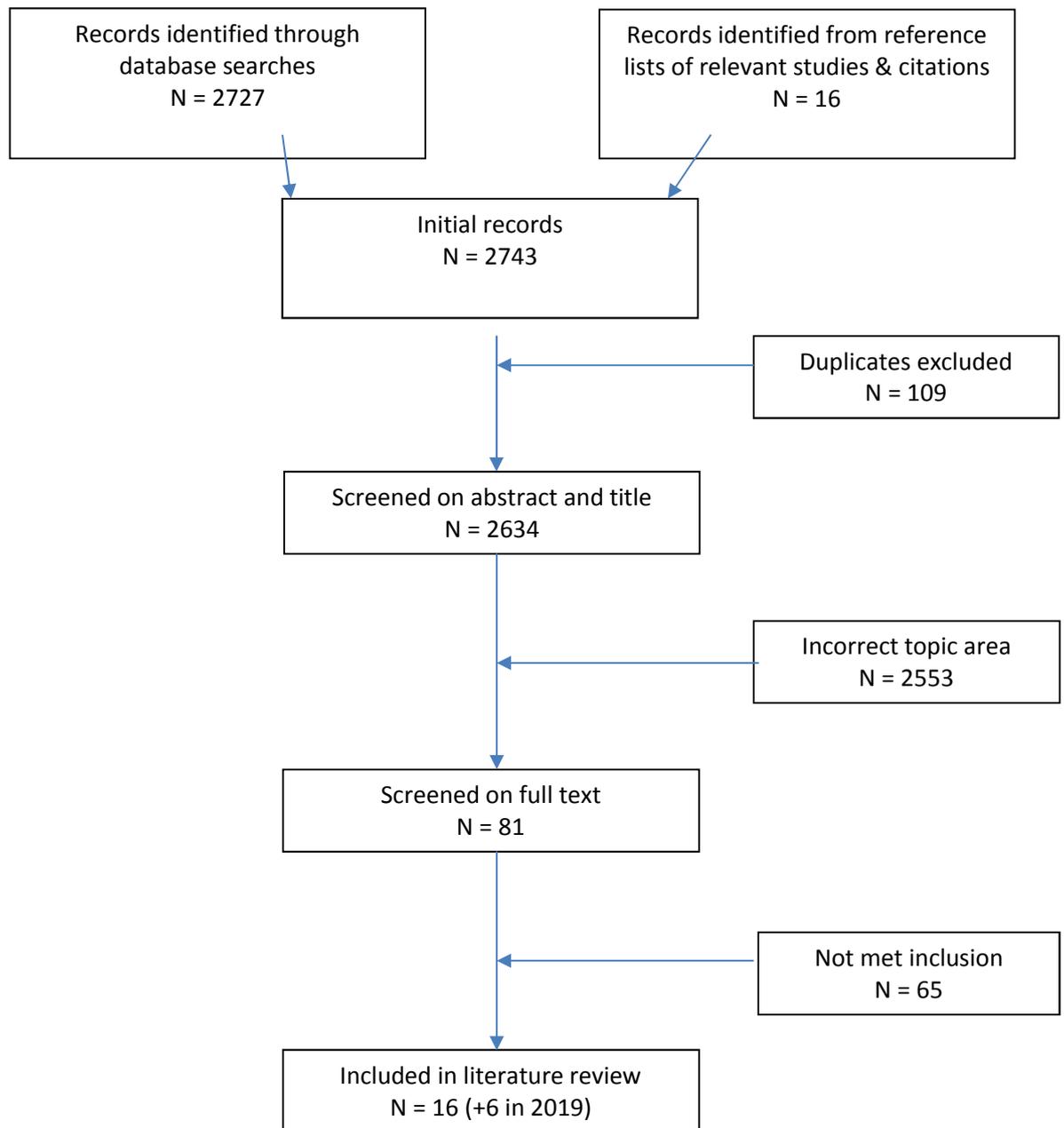
## Appendix A

- Research undertaken in acute hospitals.
- All research designs.

### Exclusion criteria:

- Studies not in acute hospital inpatient population.
- Studies that did not include mobility or independence.
- People with dementia not included

The PRISMA diagram on the following page illustrates the results from the search strategy.





## Appendix B Older people's experiences

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### Older people's experiences in acute care settings: Systematic review and synthesis of qualitative studies

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#### ABSTRACT

**Background:** There is no recent synthesis of primary research studies into older people's experiences of hospital care.

**Objective:** To synthesise qualitative research findings into older people's experiences of acute health care.

**Design:** Systematic procedures for study selection and data extraction and analysis. Comparative thematic approach with meta-ethnographic features for synthesis.

**Data sources:** Worldwide grey and published literature written in English between January 1999 and December 2018 identified from databases: CINAHL, Medline, British Nursing Index, EMBASE Psychiatry, International Bibliography of the Social Sciences, PsychINFO, and AgeInfo.

**Review methods:** Systematic review and synthesis of 61 qualitative studies and two systematic reviews describing older patients' experiences of care in acute hospital settings.

**Results:** The physical and social environment of the hospital positioned many older patients as insignificant and powerless to influence the care they received. Patients subjugated their needs to those of staff and other patients, holding back information and requests for help. Patient knowledge of the time-based schedules for care, and experiences of waiting for care and of staff limiting their time with them served to reinforce patients' feelings of insignificance and powerlessness, reflecting the perceived primacy of bureaucratic organisation of care over individual needs and preferences. Highly negative experiences would result if these aspects of context were not mediated by individualised relational work by staff, nursing staff in particular. Some groups of patients were at particular risk of negative experiences: people with dementia and/or delirium; people with difficulty communicating, hearing or understanding; people from ethnic minority groups, especially where there was a language difference; people with low functional/physical ability; people with low literacy; and people without regular visitors and/or family support. Three key features of care consistently mediated negative feelings and were linked to more positive experiences were: "maintaining identity; see who I am", "building relationships: connect with me", and "partnering in care: involve me".

**Conclusion:** Older people's care experiences in hospital may be negative in the absence of relational work by nurses to maintain people's identity, establish caring connections and ensure that individual patient needs, preferences and values are honoured in the care that is delivered. Relational care by nurses can mediate powerful institutional drivers that may otherwise result in negative experiences and poor care. Organisational and service-wide commitment are needed to create the culture and context in which relational care can flourish.

**Tweetable abstract:** Synthesis of qualitative research on older ppl's hospital experiences: hospital's physical and social environment positions older ppl as insignificant and powerless. Highly negative experiences result if impact of context not mediated by individualised relational work by nurses.

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## **Appendix C Participant Information Sheet**

### **Information about the research study:**

**“Sit down Mrs Jones”: Risk enablement and mobility for people with memory problems on an acute medical unit.**

#### **Introduction**

You are invited to take part in a student PhD project that aims to understand what it is like for a person with memory problems to be on the acute medical unit. We are particularly interested in what it is like to be less mobile and independent than usual.

The reason that you are being asked is that we want to improve how we care for people with memory problems. To do this we need you to tell us what it is like to be on the unit.

This information sheet explains this research and how it may impact upon you.

Please take time to read the following information. If you have any questions about the research then please feel free to contact Pippa Collins (the researcher) on the contact details below.

This study has Research Ethics Committee approval (17/SC/0625).

#### **What does the research involve?**

You will be asked to take part in a conversation with the researcher (Pippa Collins) where you can talk about things that are important to you. This conversation will be either video or audio recorded. We will make the recordings using a tablet and you can look at or listen to the recordings to make sure that you are happy with them.

If you would like to, we could have another conversation on the next day.

#### **Do I have to take part?**

No you do not! It is up to you. If you don't want to take part, just say no! Saying No will not affect your care or your legal rights.

#### **What if I change my mind?**

You can change your mind about taking part in this project at any time.

#### **What happens when the research study stops?**

We will gather together all the information from the conversations and will decide if it is useful in telling us how to improve the care of people with memory problems.

### **How will the videos be used?**

If you agree we will use the videos and audio recordings for promoting the results of the research and for education purposes. You are welcome to say that you do not want them used in this way.

### **Will information remain confidential?**

The information that you give us is very important and we will treat it with care. The video recordings will show your face, but your name and any information about you will not be shown. Quotes from audio recordings will not include your name or other identifiable information. Data may be accessed for monitoring and audit purposed by UHS.

The video and audio recordings will be used for education only if you agree. Otherwise they will only be viewed by the researcher. We will not use your name in our reports, and we will lock away securely all the information you give us so only the research team have access to it.

### **What if I wish to complain about the study?**

If you have a concern or complaint about this study please contact:

#### **The Research Governance**

##### **Manager**

University of Southampton,  
Building 37, Highfield,  
Southampton.  
SO17 1BJ

Tel: 023 8059 5058

Email: [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk).

##### **Patient Support Services**

Mailpoint 81  
University Hospital Southampton.  
SO16 6YD

Tel: 023 8120 6325

#### **Researcher Supervisor contact information:**

Prof Jackie Bridges  
University of Southampton  
Building 67, Highfield  
Southampton  
SO17 1BJ

Email: [jackie.bridges@soton.ac.uk](mailto:jackie.bridges@soton.ac.uk)

**Researcher contact:** Pippa Collins [pc1e13@soton.ac.uk](mailto:pc1e13@soton.ac.uk) Tel 07999 256 998

## Appendix D Consent Form

### Mobility and people with memory problems on the acute medical unit.

Researcher name: Pippa Collins

**Please read the statements and tick the box or let the researcher know if you agree or disagree**

Yes, I agree	No, I do not agree
--------------	--------------------

I have read and understood the information sheet (Version 2: 11.10.2017) and have had the opportunity to ask questions about the study. Date:

I agree to take part in this research project and agree for my data to be used for the purpose of this study.

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected

I agree to the interview being video/audio recorded

I agree to the video/audio recording being used in education or research presentations

Name of participant (print name).....

Signature of participant or signature of person witnessing verbal  
consent .....

Date.....

## **Appendix E      Consultee Information Sheet**

### **Information about the research study:**

**“Sit down, Mrs Jones”: Risk enablement and mobility for people with memory problems on an acute medical unit.**

### **Participant information sheet for carers/relatives/friends of those lacking capacity to consent**

Your relative/partner/friend is being invited to take part in a student PhD research study that aims to understand what it is like for a person with memory problems to be on the acute medical unit. We are particularly interested in what it is like to be less mobile and independent than usual.

We are asking for your advice. Your advice will help us make sure that if they indicate that they'd like to take part in the research, we can be sure this is really what they want.

This information sheet explains this research and how it may impact upon your relative/friend/partner.

Please take time to read the following information. If you have any questions about the research then please feel free to contact Pippa Collins (the researcher) on the contact details below.

This study has Research Ethics Committee approval (17/SC/0625).

### **What does the research involve?**

This research involves taking part in a conversation with the researcher (Pippa Collins) in order to talk about things that are important to your relative. This conversation will be either video or audio recorded. We will make the recordings using a tablet and you can look at or listen to the recordings to make sure that you are happy with them.

If your relative would like to, we could have another conversation on the next day.

### **Does my relative have to take part?**

No they do not! It is up to you. If you don't want them to take part, just say no! Saying No will not affect their care or their legal rights.

### **What if I change my mind?**

You can change your mind about taking part in this project at any time.

### **What happens when the research study stops?**

We will gather together all the information from the conversations and will decide if it is useful in telling us how to improve the care of people with memory problems.

### **How will the videos be used?**

If you agree we will use the videos and audio recordings for promoting the results of the research and for education purposes. You are welcome to say that you do not want them used in this way.

### **Will information remain confidential?**

The information that you give us is very important and we will treat it with care. The video recordings will show your relatives face, but their name and any information about them will not be shown. Quotes from audio recordings will not include their name or other identifiable information. This data may be accessed by UHS for auditing and monitoring.

The video and audio recordings will be used for education only if you agree. Otherwise they will only be viewed by the researcher. We will not use names in our reports, and we will lock away securely all the information you give us so only the research team have access to it.

### **What if I wish to complain about the study?**

If you have a concern or complaint about this study please contact:

#### **The Research Governance Manager**

University of Southampton,  
Building 37, Highfield,  
Southampton.

SO17 1BJ

Tel: 023 8059 5058

Email: [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk).

#### **Patient Support Services**

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#### **Researcher Supervisor contact information:**

Prof Jackie Bridges

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Building 67, Highfield

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Email: [jackie.bridges@soton.ac.uk](mailto:jackie.bridges@soton.ac.uk)

**Researcher contact information:** Pippa Collins [pc1e13@soton.ac.uk](mailto:pc1e13@soton.ac.uk)

## Appendix F Consultee declaration form

### Mobility and people with memory problems on the acute medical unit.

#### Consultee declaration form for carers/relatives/friends of those lacking capacity to consent

Please initial box

I ..... have been consulted about .....participating in this research project. I have had the opportunity to ask questions about the study and I understand what is involved.

In my opinion he/she would have no objection to taking part in the study

I understand that I can request he/she is withdrawn from the study at any time without giving any reason and that this will not affect his/her care.

I understand that audio and video recordings made during this study might be used for education as well as research purposes.

\_\_\_\_\_

\_\_\_\_\_

Relationship to participant:

Date

Signature

## Appendix G Hospital video consent form

### FILMING / VIDEO OR PHOTOGRAPHY CONSENT FORM

I hereby confirm that I give my full consent for my image and/or voice or that of my child(ren) or pupil(s) to appear, either incidentally or specifically, in video/audio/photographic and digital output produced by \_\_\_\_\_

(Brief description of the project)

\_\_\_\_\_  
\_\_\_\_\_

All material will remain the property of \_\_\_\_\_.

I understand that I will not be paid for my participation in the project nor for the use of any photographs or filmed material and that this material may be re-used or re-purposed in the future. I understand that I will have no interest in, or claim to the copyright of any material produced in relation to the project described above.

Name \_\_\_\_\_

Signature \_\_\_\_\_

(On behalf of) \_\_\_\_\_

Date \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

## Appendix H Academic and clinical undertakings

- Member of Ageing and Dementia Research cluster group UoS
- Attendee at regular Dementia, Action, Research and Education (DARE) meetings. UoS
- Poster presentation at CLAHRC Wessex event, BGS Autumn conference.
- Oral presentations 2017 BGS Autumn conference on movement disorders
- BGS Wessex 2018 oral presentation + poster
- Involvement in the hospital acute frailty network project.
- Member of the Wessex Healthy Ageing expert steering group.
- Discussion of my project with Minister of State for Health and Social Care May 2018.
- Oral presentations at 2018 and 2019 Alzheimer's Society Conferences
- Presentation of project at Alzheimer's Society legacy events.
- Teaching on MSc Complex care module and UG nursing and physiotherapy courses.
- Peer reviewer for International Journal of Older People Nursing.
- Participant at DTC summer school in Sweden.
- Principal Investigator at UHS for NIHR study (Featherstone et al 2019).
- Part of the Inspirational Voices public engagement project 2018
- Part of HSJ Judging panel for patient safety 2019
- Dementia Researcher podcast May 2019
- Deputy Digital Media Editor for the British Geriatric Society 2020 onwards.

### **Publications**

Bridges J, Collins P, Flatley M, Hope J, Young A (2019) Older people's experiences in acute care settings: systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies* <https://doi.org/10.1016/j.ijnurstu.2019.103469>

Collins P. (2020) Stories of (Im)mobility: People Affected by Dementia on an Acute Medical Unit. In: Vindrola-Padros C, Vindrola-Padros B, Lee-Crossett K, (eds.) *Immobility and Medicine - Exploring Stillness, Waiting and the In-Between*. Palgrave Macmillan.

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