Well-being and expression of self in dementia: interactions in long-term wards and creative sessions.

Fiona Kelly

Thesis submitted for the degree of Doctor of Philosophy

University of Stirling

2007

Declaration

I declare that none of the work contained within this thesis has been submitted for any other degree at any other university. The contents herein have been composed by the candidate; Fiona Kelly.

Fiona Kelly

For my father; John Kelly RHA
Artist, printmaker
1932-2006

Acknowledgements

Thank you to all who have supported and encouraged me from the inception of this thesis to its completion.

Thank you to John Killick and professor Alison Bowes, who in different ways set me along this path.

Warm thanks to my supervisors; professor Alison Bowes, professor Sally Wyke and doctor Anthea Innes, who have supported, motivated and challenged me throughout the past three years.

Thanks to my friends, family and fellow NMAHP Ph.D. students for supporting me through some tough times. Thanks particularly to my sons Eoin and Jack, for uncomplainingly fending for themselves.

Thanks to the NMAHP consortium; comprising NHS Scotland, The Health Foundation and the Scottish Executive for their generous financial support, training and networking opportunities.

Finally, thank you to the managers and staff of Moorhills Hospital for allowing me to carry out my fieldwork, and especially to the patients who welcomed me into their world and taught me resilience of spirit.

Abstract

This is a multi-method ethnographic study, grounded in symbolic interactionism and social constructionism, which seeks to explore the social worlds of people with dementia in institutional long-term care. Carried out over six months, it uses non-participant observation, Dementia Care Mapping, video-recording, focused conversations and extensive fieldnotes to document types of interactions that fourteen people with dementia received in everyday ward life and during weekly creative sessions facilitated by occupational therapy (OT) staff. Using Kitwood's (1997) work on person-centred care and Sabat's (2001) work on selfhood (Selfs 1-3) it identifies their responses to such interactions in terms of their well or ill-being and expressions of Self.

The study shows that everyday staff interactions with participants, while sometimes positive, were more often limited in their potential for maintaining or increasing well-being. Sometimes staff interactions were abusive; causing participant ill-being. Participants expressed Selfs 1-3 verbally and visually, although some of these expressions were subtle, fleeting and fragile.

During creative sessions, OT staff engaged in sustained positive interactions, raising participant well-being and facilitating Self-expression; a fragile expression of Self could become a robust expression of Self, a past Self could be reclaimed and a desired Self co-constructed.

My findings suggest that, in their interactions during creative sessions, OT staff generally recognised and supported Self of participants, raising well-being. However, ward staff did not fully recognise and therefore could not support Self in their interactions with participants, resulting in participant ill-being. This is a crucial finding, which could partially explain the differences in interaction types I observed, and the corresponding differences in participant well-being and Self-expression.

This thesis argues for integrating the selfhood and person-centred approaches into an innovative staff-training programme, in order to bring about transformational change in practice. This might encourage care staff to reach out, recognise and respond to aspects of Self as they carry out care; promoting more positive ways of interacting with their patients, increasing patient well-being and fostering staff satisfaction.

Table of Contents

List of Tables

Chapter 1: Introduction to thesis

Introduction

Dementia is an umbrella term for several degenerative brain conditions including Alzheimer's disease, multi-infarct dementia, Lewy body dementia and Korsakoff's syndrome. All of these conditions involve variable, progressive loss of cognitive function; beginning with forgetfulness and difficulty concentrating, and progressing to difficulties with reasoning, communicating, recognition and mobility. Dementia; meaning "to be out of one's mind", can be devastating for the person and his/her family, bringing with it the threat of loss; of autonomy, a certain future and ultimately the perceived threat of loss of identity. Christine Bryden (2005:156), in her powerful story of her journey with dementia, talks of her fear of ceasing to be:

> *We all believe the toxic lie of dementia; that the mind is absent and the body is an empty shell. Our sense of self is shattered with this new label of dementia. Who am I, if I can no longer be a valued member of society? What if I don't know who I am and who I was?*

Loss of self is a persistent notion in everyday thinking about dementia, although increasingly, carers, practitioners, philosophers and academics are turning away from this view of identity, towards one in which interdependence and relationships contribute towards maintenance of self.

In this thesis, which has been a personal journey of discovery, I examine the everyday lives of people with dementia living in institutional long-term care. I explore and compare their responses, in terms of well or ill-being and expressions of Self, to different types of interaction they experience both in the wards and during weekly creative sessions facilitated by occupational therapy staff. I will show that Self is not lost as dementia progresses, but that its often-fragile expression is contingent on the receptiveness of others within interaction. Thus, while selfhood endures, it is often unrecognised and unsupported by ward staff; resulting in participant ill-being.

In this chapter, I will present a brief personal and professional biography in order to give my interest in dementia some context. Then I will discuss models of understanding dementia, point to gaps in the literature, briefly discuss different understandings of ageing and reflect on the evolution of my research questions before introducing the remaining chapters of this thesis.

Personal and professional background

I grew up in Dublin, the oldest daughter of six girls. One of my earliest memories is sneaking upstairs to get a glimpse of my father's studio, in which was a messy world of clutter and colour, and it was my first introduction into his life as an artist. My father, although a wonderful storyteller, struggled to express his deepest self verbally, but through his work, I now get a glimpse into the sorrows and joys of his life. We had many conversations on the nature of art and creativity and he continued to inspire and encourage me with my Ph.D. until his death in 2006.

I trained as a general nurse in a teaching hospital in Dublin. When I qualified in the mid 1980s, there was high unemployment and many nurses left Ireland to find work abroad. I came to the UK to train as a midwife. Here was my first experience of person-centred care, or rather woman-centred care; for, as part of our role, we were encouraged and expected to spend time talking with the women in our care. This was a revelation to me as, during my nursing training, sitting talking to patients was discouraged in favour of cleaning cupboards. I worked for several years as a midwife and celebrated the privilege of delivering each new life into the world.

Cuts in the midwifery service forced me to leave midwifery and find a job elsewhere. By chance or design, I found work in a local nursing home and, 14 years on, I still work there caring for people with dementia. Here, in this place of holism and love, was my second and most profound experience of person-centred care.

My life also took an academic route, in parallel with my nursing practice, and I completed a B.Sc. in psychology in 2003. During these years, I met practitioners, both in the nursing home and in my academic life, who enthusiastically tried to engage with people with dementia through poetry, music and art. This resonated with my childhood memories of seeing my father's agony and relief as he strived to express his deepest being through art and it drove me to question whether there might also be a relationship between creativity, well-being and self-expression of people with dementia. A meeting, in 2002, with John Killick at the Dementia Services Development Centre at the

University of Stirling, sowed the seeds for this research; seeds which developed with a subsequent Master's dissertation and which have been refined through the three years of this Ph.D.

Having read widely in sociological, nursing and art therapy journals, I realised that, while writers extolled the benefits of creativity for people with dementia, there was little empirical evidence for such benefits and little research into the benefits of creativity for people in hospitalised long-term care. Here, was an opportunity to link my love of working with people with dementia with an increasing interest in sociological research, and to use my personal experience of growing up with someone who struggled for self-expression, but who found it through painting.

Models of dementia

There are different ways of understanding dementia; each having different implications for the person with dementia and for how they are supported (Downs et al., 2006). I will describe two models, which inform thinking and practice; the biomedical and the dialectical models of dementia.

Biomedical understanding of dementia

The biomedical model, which views dementia in terms of cognitive and functional decline, has been dominant in western cultures through most of the 20th century (Downs et al., 2006). Within this understanding, neurodegenerative changes in the brain result in progressive cognitive decline, leading eventually to death. Such cognitive decline, resulting in difficulties in remembering, reasoning and decision-making, are seen as problematic; requiring treatment

from the medical profession (Bond, 1992). The person with dementia becomes positioned as a patient, sufferer or victim with, traditionally, an emphasis on the burden that informal carers experience (Twigg and Atkin, 1994). Treatment is prescriptive; being the preserve of psychiatrists and geriatricians. Medicalisation of symptoms is one of the most controversial aspects of old age psychiatry (Downs et al., 2006), often with medication being administered covertly (Øyvind, 2007), and prescribed in isolation to consideration of psycho-social contributors to "challenging behaviours". For example, Tunis et al. (2002:151), in relation to "behavioural and psychological symptoms of dementia", advocate the use of antipsychotic drugs and assert that:

> *…it is critical that we effectively identify and treat those aspects of the disease most closely linked to both individual (patient, family member, faculty staff) and societal burden.*

The biomedicalisation of dementia can result in social death (Lyman, 1989), to institutionalisation and exclusion of people with dementia (Cantley and Bowes, 2004) and places little emphasis on recognising or nurturing their personhoods (Kitwood, 1997).

Dialectical understanding of dementia

Kitwood (1997), arguing against the determinism of the biomedical model, proposed that the symptoms and behavioural changes associated with dementia do not arise purely from neuropathology, but from a dialectical interplay between neuropathology and the person's psycho-social environment. The most disabling effects are to be found, not in the disease process itself, but in the threats to one's personhood, brought about by the negative interactions of

others. Kitwood's (1997:46) work was pivotal in implicating the interactions of caregivers in contributing to "depersonalisation" and ill-being of people with dementia. He has been instrumental in calling for recognition of an enduring personhood and arguing for the centrality of the person within person-centred care.

My research, recognising the determinism of the biomedical model, focuses on a psycho-social understanding of dementia and uses symbolic interactionism and social constructionism to try to understand what it is like to be a person with dementia in institutional care. It is grounded in Tom Kitwood's (1997) person-centred approach to care and Steven Sabat's (2001) social constructionist approach to selfhood; the threads of which run throughout this thesis. I will discuss these approaches in chapter 3.

Relevant research

The biomedical approach, with its emphasis on objectivity, rationality and experimental research designs, continues to dominate dementia research. However, there has been an increasing shift from research which focuses on cognitive and functional decline to research which seeks to understand the subjective experiences of people with dementia (Goldsmith, 1996; Downs, 1997; Wilkinson, 2002; Hubbard et al., 2002a; Cotrell and Hooker, 2005). There is also an increasing body of work written by people with dementia themselves (Friedell, 2002; Sterin, 2002; Bryden, 2005), which gives insight into many aspects of living with dementia. However, there is a dearth of literature exploring the world of those with more severe cognitive decline (Cowdell, 2006)

in long-term hospitalised care. This research aims to address some of these gaps.

With an increasing focus on identity and self as dementia progresses, researchers have used different conceptualisations of self and different methods for assessing self in dementia. Some have explored autobiographical memory and continuity of identity (Addis and Tippett, 2004), self in discourse (Small et al., 1998; Snyder, 2006) and narrations of self through life stories (Usita et al., 1998). Others have explored managing a sense of self in early Alzheimer's (Pearce et al., 2002), managing threats to self (Clare, 2003) and preservation of self following diagnosis (Beard, 2004).

Some researchers have focused on expression of self in people with dementia in long-term care. For example, Small et al. (1998) explored verbal and non-verbal expressions of self in participants in a nursing home; concluding that participants, even with severe cognitive decline, indexed aspects of self in different ways. Tappen et al. (1999) tape-recorded conversations with people with Alzheimer's in a nursing home and concluded that, even those with significant decline referred to themselves, using first person indexicals "I". Kontos (2004), in an ethnographic study of participants in long-term care proposed that self resided in idiosyncratic bodily movements and gestures. There is, however, an absence of research which explores expression of Selfs 1-3 following Sabat (2001); particularly in exploring the relationship between the interactions experienced by participants in institutional care and their responses to such interactions in terms of their well/ill-being and Self-expression.

My research, examining interactions experienced by people with dementia in institutional care, also sought to explore participants' experiences of taking part in creative sessions, facilitated by occupational therapy staff. I was interested in how both the process of painting and interacting, and the product, might influence participants' well-being and Self-expression.

There is a body of literature describing the work of art therapists and occupational therapists who provide creative activities for people with dementia (Osler, 1988; Leslie, 2001; Wood, 2002; Mottram, 2003). However, little of the literature is research-based. For example, while many of the authors talk discursively of benefits, improvements, potentials and therapeutic outcomes of various kinds, they provide little in the way of methodology, data or analysis to support the inferences made about the "success" of the creative input under investigation. I will discuss this further in chapter 3.

This research aims to extend and integrate the body of literature on person-centred care, selfhood and creativity, focusing specifically on those living with dementia in hospitalised long-term care.

Ageing and identity

As many people with dementia are also ageing, it is useful to briefly consider how they may be positioned by social assumptions and practices relating to ageing. In this section, I describe two approaches to understanding ageing and old age; biomedical and psycho-social, in order to provide a deeper understanding of living with dementia while also ageing.

Biomedical approach towards ageing

With the emergence of gerontology in the early twentieth century, old age became a focus of study within the biomedical realm (Kontos, 1998). Ageing became constructed as a medical problem (Haveven, 1995), often requiring medical management through drugs or institutionalization. This, the biomedicalization of ageing, has resulted in society viewing ageing as pathological and certainly as undesirable (Estes and Binney, 1989). While Estes and Binney (1989) offer due respect to biomedicine for its contribution to health care, they criticise its extension to and control over the ageing process, and its consequent construction of ageing in terms of decremental physical decline.

Bond and Corner (2004) point out that many health professionals' experiences of older people continue to be those of illness and disease; fostering the notion that ageing is synonymous with disease. Thus, the biomedical understanding of ageing, accompanied by its own terms of analyses (Boyle, 2000) often positions ageing people as in a state of biological decline, rather than as persons with remaining potential. Further, medical practitioners regularly make judgements about older people's competencies based on single assessment (McCormack, 2004) or make stigmatising (Goffman, 1968) and defining reference to a condition, for example "demented" in which they position people with reference to specific needs rather than viewing the person as a whole. Such ways of conceiving of older people can result in them being treated as "things" rather than as persons (McCormack, 2004).

Within the field of social gerontology, there has been growing unease at the biomedicalization of ageing (Estes and Binney, 1989) and the focus is increasingly on the ethics of biomedicalization (Kaufman et al., 2004) and the socio-cultural aspects of ageing (Kontos, 1998). There is an increasing emphasis on person-centred practice (McCormack, 2004), on seeing the person behind the patient through the sharing of experiences and life stories (Clarke et al., 2003) and on promoting empowering care as opposed to disempowering care (Faulkner, 2001). For as Coleman et al. (1993:10) propose:

> *Long life should not be something to be afraid of, but an achievement to be enjoyed.*

There are the seeds, here, of a culture of enablement, which is slowly replacing that of dependency. However, as Dewing (2004) suggests, working within frameworks of personhood and enablement present challenges for those who continue to work within contemporary health care systems which are dominated by performance targets and time management pressures.

Psycho-social understanding of ageing

Historically, caring for frail older people has involved institutionalization (McCormack, 2004), in order to hide them from the living (Elias, 1985). This can result in isolation (Nolan et al., 1995) resulting in depersonalization (Kitwood, 1997). Armstrong-Esther et al. (1994:271) reinforce these ideas with their findings that social interaction between staff and institutional elderly was minimal; being focused on tasks. Patients spent the majority of their time alone. They conclude that:

In most cases, what we offer is a life sentence with patients sitting clean and quietly rather than a lifestyle that, whenever possible, promotes the major goals of adulthood such as activity, independence and interdependence through engagement.

Similarly, Bury and Holme (1991:115) highlighted patients' isolation in their description of many institutions for older people in which "there appeared to be nothing other than the inevitable television". Norbergh et al. (2001:215) also conclude that those placed in psycho-geriatric care live a "life in solitude for most of the time".

Much empirical research in psychology has proceeded with the assumption of cognitive decline as old age advances (Coleman, 1993). There is, however, debate about the extent of psychological decline with ageing (Hurd, 1999), with particular concern expressed that researchers do not take sufficient consideration of the effects of physical illness on the ability to perform cognitive tests proficiently (Coleman, 1993). Psychological research has also underestimated positive changes that can occur with ageing such as increased wisdom, experience or creativity. Indeed, Maduro (1974) found, in the Brahmin folk painters of Rajistan, that creativity seemed to peak in middle age and remained constant into older age. Waid and Frazier (2003) reinforce this position by arguing that older people, themselves, see later life, not in terms of cognitive decline, but as a time when they can develop and expand their abilities and possible selves.

In a discursive approach to old age, Holstein and Gubrium (2000) suggest that the self emerges through narrative; that narrative acts as a link between the past and the present personal history of a person. Stories of the self arise through the interplay of discursive practice; seeing selfhood as a work in progress, and through discourse-in-practice; reflecting existing social structures which shape personal identity. Gubrium and Holstein (1999) describe the nursing home as being a discursive anchor for the ageing body. Because the body is framed, observed and monitored, catalogued and evaluated, it becomes a site of identity. A person will age bodily as much through the passing of time as through the anchoring discourse of an institution such as a nursing home, which influences how others think and talk about the ageing body. Thus, there is an interplay between one's own discourse and the discourse of others in constructing one's sense of an ageing self.

Within sociological literature, are two normalising, yet competing theories of ageing: disengagement theory and activity or successful ageing theory. The disengagement theory of Cumming and Henry (1961) viewed the older person's withdrawal from society as a natural process of ageing; in which the person severs relationships and ties in order to prepare society for her/his imminent demise. From this perspective, such experiences as powerlessness, dependency, loneliness and loss of purpose, role and status are natural phenomena of ageing. This approach has been criticised for its assumption that older people initiate the disengagement process as opposed to considering how society and social structures might negatively influence opportunities for engagement (Coleman et al., 1993).

Tornstam (1997) has put forward another explanation for the perceived withdrawal of older people; with the notion of gerotranscendence, which he describes as the contemplative dimension of ageing. He argues that, as part of the process of maturation, a shift occurs in the perspective of the person; from a materialistic, pragmatic viewpoint towards a process of contemplative change and development. Sherman and Webb (1994) also describe this aspect of ageing as a spiritual journey. They describe how, in the narratives of older people, they move from seeing themselves as possessors and as having attachments to seeing themselves as part of a process of becoming. These interpretations of the detachment of some older people from the ties of society are more akin to an eastern understanding of the self-as-process; as "moving towards being" (Sherman and Webb, 1994:264). However, despite such alternative viewpoints, disengagement theory has remained the dominant interpretation of the perceived negative aspects of ageing such as detachment and solitude.

In opposition to disengagement theory is activity theory, which promotes successful ageing (Gingold, 1992) and which argues that successful ageing can be achieved by maintaining the activity and patterns of middle life. The message in activity theory is that if you stay active you will be happy and fulfilled. The representation of healthy, happy, active older couples reinforces the demand that one must age successfully. However, activity theory, while having laudable aims, has also been criticised: for being too idealistic (Bond et al., 1993; Andrews, 1999; McHugh, 2003) and for potentially forcing "middle-class moral and family-oriented" activities onto older people (Katz, 2000:143).

Successful ageing rests on the notion of successful adaptation; to role or to physical, structural or environmental changes. However, Andrews (1999) questions whether adaptation should not be reconceptualised as conformity. Andrews (1999) challenges ageist culture and argues that old age does exist and should not be wished away, for to do so is to deny the years that have made people who they are, and is in itself ageist. The challenge is, not to conquer old age; for without a lifetime behind us, we have no history, no story and no self, but to challenge the ageist culture to which we belong.

Finally, in understanding ageing, I take a lesson from Rentsch (1997), who questions prevailing understandings of ageing and asks that society turn the tables on understanding old age. Rather than asking how someone who is frail, restricted, disadvantaged, slow or dependent is able to cope in a society, which is rapidly changing, technological, complex and sophisticated, we should instead be asking what society can learn from the experiences, meanings and facts of ageing. We must "learn a lesson in modesty" (Rentsch, 1997:271). We must learn that faster, louder, more and more complex, more and more technological, more and more perfect will remain existentially and ethically nothing more than a system which is designed to quantify, produce, consume and dominate (Rentsch, 1997). Instead, we must learn the value of slowness, of pausing and reflecting, of temporality, of corporeality and of finitude. I aim to follow Rentsch, both in my study and in my practice.

Development of research questions

I originally set out to examine the relationship between the process and the product of creativity, and well-being and Self-expression of people with

dementia in institutional long-term care. The rationale being that, while many claimed the value of creativity, there was little rigorous research-based investigation to support its increasing use.

On starting fieldwork, I realised that my focus on creativity assumed a quality of care and level of staff interaction that did not consistently happen. What seemed of greater consequence to the lives of participants were the types of interactions they experienced, both in the wards and during creative sessions, and what became important for me was to examine the relationship between such interactions and participants' well-being and Self-expression. Thus, the focus of the study moved from seeking a relationship between creativity, well-being and Self-expression, to one that explores the role of interactions in everyday ward life as well as during creative sessions in influencing well-being and facilitating or stifling Self-expression.

Research questions

Thus, my research questions are:

- What types of interaction occur in wards and creative sessions?

- What are participants' well-being levels in wards and during creative sessions and what factors influence well-being?

- How do participants with dementia express Self in wards and during creative sessions and what factors influence Self-expression?

- What is the relationship between interaction types, well-being and Self-expression?

- What are the implications of the research findings for practice and policy?

Introduction to thesis chapters

In chapter 2, I lay out the theoretical foundations of the thesis: symbolic interactionism and social constructionism. I outline their origins and assumptions, and some of the criticisms aimed at them both. I indicate the value of both positions in grounding my research; stressing their appropriateness, both in terms of theory and methodology, in exploring interactions experienced by participants and their responses to such interactions in terms of well/ill-being and Self-expression.

In chapter 3, I present the central ideas on which the thesis is based: Kitwood's (1997) person-centred approach and Sabat's (2001) work on selfhood. I discuss Kitwood's (1997) work on negative and positive aspects of interaction, which can either undermine or uphold personhood in people with dementia. I then describe Sabat's (2001) understanding of selfhood: Selfs 1-3. I discuss philosophical and social influences on ideas of loss or maintenance of self, before briefly discussing the changing culture of dementia care. As person-centred care is not easy to sustain in the care of people with dementia, I propose creativity as another means to facilitate person-centred interaction. I explore the different approaches to art therapy taken by American and British art therapists before looking at claims for therapeutic benefits of creative sessions; such as increased well-being, heightened communication and expression of self. I conclude by highlighting shortcomings in much of the

literature which explores creativity and dementia; in terms of its conceptualisation, methodology and analysis.

In chapter 4, I discuss ethnography as my methodological approach; supporting my epistemological position that I might gain a deeper understanding of participants' social worlds by engaging with them and observing their everyday experiences in the wards and during creative sessions. I discuss the research design, choice of research setting and how I gained ethical approval. I present Dementia Care Mapping (DCM), video-recording, focused conversations with participants and keeping extensive fieldnotes as my methods for data-collection. Finally, I describe analysis and management of data.

In chapter 5, I describe the three wards in which I carried out fieldwork. I describe staffing levels in each ward and introduce the 14 participants, the art therapist and occupational therapy staff. I give a detailed account of how I gained consent from all participants, and I reflect on difficulties and dilemmas that I encountered during fieldwork, on how I will have changed the research setting and on how the setting impacted on me as nurse, researcher and humane being.

Chapter 6 is the first of the two findings chapters; in which I use extracts from fieldnotes, DCM notes and conversations with participants to illustrate the analysis. In this chapter; using Kitwood's (1997) elements of malignant social psychology and positive person work as identifiers of interaction types, I describe the types of interaction that I observed between staff and participants

in the three wards and during and after creative sessions. I also describe participants' levels of well/ill-being in the wards and during creative sessions; in relation to the different types of interaction they experienced.

In chapter 7, the second findings chapter, I describe my observations of participants' verbal and visual expressions of Self; in wards, during creative sessions and after creative sessions. I elaborate on Sabat's work and show that many expressions of Self were fragile, particularly in those with the most cognitive difficulty, and I propose that the quality of participants' Self-expression depended on whether staff, through their interactions with participants, recognised and supported Self.

In the final chapter, I discuss my findings in relation to the research questions and link some of the findings to previously discussed theory and research. I discuss some limitations and strengths of the study before laying out my central thesis, which argues for integrating the person-centred and selfhood approaches into a staff training programme in order to encourage ways of interacting which enhance well-being of people with dementia. I then set out what I consider to be key messages to practitioners, policy-makers and academics. Finally, I discuss how this study has contributed to knowledge about dementia and dementia care, and I suggest areas for further research.

Chapter 2: Theoretical frameworks

Introduction

As I sought to understand how the interactions of others might influence well-being and Self-expression of people with dementia in institutional long-term care, I chose two broadly interpretivist approaches; symbolic interactionism and social constructionism on which to ground my work. Symbolic interactionism is a useful approach for understanding how shared meanings ascribed to language, actions and objects both determine self and are determined by self through interaction with others. Social constructionism builds on symbolic interactionism and examines wider society, with its institutions and belief systems, in contributing to the construction of self. In this thesis, I draw on both approaches in analysing the data and in interpreting my findings. I will give a brief overview of both approaches below.

Symbolic interactionism

Symbolic interactionism was primarily influenced by the writings of Mead (Meltzer et al., 1980) and later elaborated on by Blumer (1962; 1969). Although diverse as a field, symbolic interactionists regard human beings as organisms who learn about their environment through symbolic interaction with others. It is through shared symbols, such as language, actions or objects, which are intentionally used to communicate or represent something to others, (Charon, 2007) that individuals are socialised.

From a symbolic interactionist position, the individual and society are inseparable, therefore an understanding of one requires an understanding of the other. As Meltzer et al. (1980) propose, society itself is constructed out of the behaviour of humans who actively play a part in developing and maintaining the socially acceptable limits to be placed on our behaviour. Behaviour is an active, circular, constructing process in which we try to make sense of our social and physical environments and the meanings attached to these environments. Meanings that social objects have (for example other humans, society, culture, language and the activities of others) emerge from shared interaction and are "handled in and modified through" an interpretative process which we then use to deal with whatever situation we encounter (Blumer, 1969:4). Such meanings are central for behaviour and interaction, in which we seek to understand the meanings of each others' actions. We do this by taking "the role of the other" (Mead, 1934); by imaginatively moving beyond our own points of view in order to define situations as if we were the other person. By taking the role of the other, we are able to define others' intentions and actions and we are able to determine how we ourselves will act on such intentions and actions (Charon, 2007).

Blumer (1969) identified three lines of meaning which are applied to an action. First the action signifies what the person making the action plans to do, second it signifies what the person to whom it is directed is to do and third it signifies joint action that arises from the actions of both parties. Meanings are derived through a continuous interpretive process, which follows from social interaction (Blumer, 1969). However, meanings are not just held by the actor, they are also

held by observers. Rosenhan (1973) illustrates the power of roles (Goffman, 1968) and role attribution made by the observer in his classic description of his and his peers' admission to a psychiatric ward. They behaved as though they were hearing voices and were diagnosed as schizophrenic. As soon as they were admitted, they stopped displaying their pseudo-insane behaviour and instead behaved as they normally would. Yet, the schizophrenic role they had taken on stuck with them, and the staffs' expectations of behaviour pertaining to that role persisted despite a revoking of the role by Rosenhan and his peers. This highlights the importance of effective communication for meaningful, reciprocal interaction. When confusion or misunderstanding occurs along any one of Blumer's (1969) lines of meaning, (as occurred with Rosenhan, 1973), communication will be ineffective, interaction will be impeded and joint interaction will fail. People, such as the psychiatric staff, faced with such breakdown in joint interaction will interpret this situation, not in the light of antecedent factors, but according to assessments of the patterns of behaviour encountered in that particular situation (Blumer, 1962). Such negative labelling may insidiously influence the person who is labelled, to act and behave in ways that actually reinforce the characteristics of the label, thus negatively moulding identity (Berger, 1963).

People are positioned in terms of the matrix of social relations they have with others, in the internalised conversations of shared gestures and in the communication of shared symbols which are directed not only to others but also towards the individuals themselves (Mead, 1934). In these conversations of gestures and symbols, what is communicated by a person evokes responses in

others which in turn alter that person's actions in a transactional and recursive process between objective and subjective reality. However, not only will people's actions be altered, their identities may also be altered as they become "different others-to-others", behaving differently in different alterations of identity and consequently experiencing themselves in different ways too (Laing and Esteron, 1964:20). Thus, the world of everyday life not only assumes a reality for people, but it also originates from their own thoughts, actions and communications and is maintained as real by these (Berger and Luckmann, 1966).

As discourse and interaction are the major ways in which we account for our actions, beliefs, ideologies and events that occur around us, our sensitivities to our own and other people's reactions to such discourse impact either positively or negatively on our identity and self-esteem. In some cases a person, who faces overpowering social demands to conform, will attempt to preserve a sense of identity by employing other-directed "false selves" who act to please others and who serve to protect the true self: that part of our identity that we strive to hold on to (Hochschild,1983).

However, symbolic interactionism does not allow room for the influence of wider society in general; its institutions and ideologies, and their part in shaping individual interactions, nor is it critical of social processes (Harding and Palfrey, 1997). For these reasons, it is necessary to turn to another interpretivist perspective; one which builds on symbolic interactionism, but which develops an understanding of how wider social and institutional processes at different

times and in different societies contribute to construction of the self. This position is social constructionism; to which I turn below.

Social constructionism

Social constructionism is not a unified school of thought. It is a broad movement, which seeks to explore and question a whole range of apparently self-evident and stable realities (Bury, 1986). While realists hold that an objective world exists independently of our representations, social constructionists argue that such objectivity is impossible; that reality is both subjective and relative (Snyder, 2006) and is formed from people's situated, shared views and meanings.

Like symbolic interactionism, social constructionism sees social interactions as its subject of enquiry, but, unlike symbolic interactionism, it assumes as problematic the very issues, which seemed uninteresting and unquestioned by previous writers (Wright and Treacher, 1982). For example, social constructionists would question how and why it should be that certain areas of human life come, or cease, to be regarded as medical. They seek to examine how meanings are formed and then reflected "on to and in to" the individual (Harding and Palfrey, 1997:11) and how people come to understand, describe, explain or make sense of themselves and the world in which they live.

Schools of constructionist thought

Harding and Palfrey (1997) divide social constructionism into two broad schools, as described below.

First is post-modernist social constructionism, which places its emphasis on language in the construction of the self. Shotter (1989) is one such proponent who argues for the construction of the person through language. In accounting for ourselves, we must always meet the demands placed on us by our status as responsible members of society. We must talk in ways that are intelligible and legitimate in the eyes of others. Shotter (1985) proposes that if we do not meet these demands we will be sanctioned and treated as socially incompetent. This presents us with a double concern; of accounting for ourselves as persons and of being constituted as persons by others in moment-by-moment patterns of communication and relations. Therefore, language is more than a symbol for communicating information and intent; it is also formative, in that the person addressed as "you" can be "moved linguistically" into behaving and reacting to circumstances in socially acceptable and recognised ways (Shotter, 1989:148). Thus, through identity talk; our "self-identifying work in interaction" (Hadden and Lester, 1978:354), we do not merely add to previous identifying activities, but continually construct and reconstruct who we are, how we became who we are and who we might be in the future.

Second is psychological social constructionism, which makes the distinction between "person"; the socially defined, publicly visible, embodied being and "self", one's singular inner being capable of autonomy and agency, and possessing a personal, unique history. This strand of social constructionism is useful in understanding the construction of self of those with cognitive difficulties and, as such, is relevant to this thesis.

This strand of social constructionism stresses reciprocity and co-construction with others in order to actualise identity. Laing (1961) suggests that the process of complementarity contributes to people's positioning by others and to their acceptance of their positioning. Within this feature of "relatedness", the "other" is needed to fulfil or complete one's sense of self. Any action, gesture, feeling, need or role is the complement of a corresponding action, gesture, feeling, need or role of the "other". Thus, interaction involves a reciprocal process whereby the self is both receiver and giver and the "other" is also needed as both receiver and giver. Our sense of self is constructed through such interactions.

Laing (1961) also suggests the processes of confirmation or disconfirmation as influencing a person's sense of self. Here, even the slightest sign of recognition from another person will confirm one's existence in that person's world. In contrast, disconfirmation will deny that person his/her existence in the other's world, thus placing the self in an untenable position. At different times in a person's life, the need for and modes of confirmation or disconfirmation will vary considerably, and will existentially influence a sense of self. This idea is reinforced by Kondo's (1990) notion of the fragmented self and by Sabat and Harré's (1992) assertion that each person has many selves, presented in different contexts and requiring recognition, acknowledgement and co-operation in order to maintain some cohesiveness of self. Identity, then, is socially constructed. I will return to this in chapter 3.

Assumptions of social constructionism

Its diversity as a set of ideas is such that different strands of constructionism will hold one or more of the following assumptions, all of which are useful in understanding dementia and the construction of self.

What we take to be our experiences of the world does not in itself determine our understanding of the world. Instead, social constructionism challenges sociologists to view taken-for-granted events or processes as being shaped by complex historical, social and cultural forces (Gergen, 1985).

A psychological strand of social constructionism assumes the primacy of the "person-in-context" (Mancuso, 1996:51) and seeks to explain the processes through which local realities of everyday life become the personal realities by which people seek to be defined in their actions and interactions.

The terms by which the world is understood are "social artefacts" (Gergen, 1985:267): they are the products of historically situated interchanges and communications between people throughout different social and cultural periods. As understandings and discourses change over time, so too do people's constructions of themselves and their world change over time. Thus, knowledge is not a stable entity; it is the outcome of negotiation and struggle (Bury, 1986).

As beliefs, understandings and constructions change over time, this implies that the rules for "what counts as what" also change over time. Thus, rules are ambiguous, potentially changing and free to vary with the "predilections" of those who make and use them (Gergen, 1985:268). "Facts" then become the means for gaining social control (Zola, 1972).

Through negotiation of meanings and constructions, certain patterns are supported to the exclusion of others. For example: seeing depression as an emotion, which is involuntarily expressed, is far different to seeing it as an emotion which is chosen and played out (Gergen, 1985). Thus, questions can be raised about the implications for society and individuals of viewing processes and practices in one way as opposed to another.

People may be seen as "cultural carriers"; they are influenced by their cultural surroundings. Thus, culture creates the base character of individual and social functioning; it shapes human lives, actions, discourses and practices. This is achieved through language; in which a person's behaviour is shaped by the linguistic manoeuvrings of others (Shotter, 1989).

In more radical constructionist thought, individuals may actually be seen as embedded within and sustained or oppressed by cultural and social processes and hierarchical institutional relations (Harding and Palfrey, 1997; Kitwood, 1997; Hughes, 2002). For example, Kitwood's (1997) identification of negative aspects of interaction which can damage personhood was a radical departure

from the prevailing understanding of dementia; in which neuropathology alone accounted for cognitive decline. In social constructionist terms, Kitwood committed himself as a rebel (Hacking, 1999) by actively campaigning for changes in the thinking and practices of care staff.

I locate myself within all of these assumptions. I consider the social world to be shaped by cultural, historical and social forces and practices; constructed by people's actions, negotiations and manoeuvrings, and also constructing and sometimes constraining their own lives. I understand dementia, in these terms, as a construction which carries with it different understandings, attitudes and ways of behaving towards those with dementia. I position myself as a rebel by proposing that people with advanced dementia can become enmeshed within a limited understanding of dementia and risk ill-being when their selfhoods are unrecognised and unsupported by those who care for them. This is not to deny the very real cognitive and physical challenges that people with dementia face; rather it is to point to the role that others play (through their understandings-based interactions) in shaping, for better or worse, the lives of those with advanced dementia.

My stance as a researcher

Both schools of thought have been criticised; symbolic interactionism for its relatively uncritical stance (Harding and Palfrey, 1997), and social constructionism for relativism (Bury, 1986) and for potentially denying the very real biological or genetic influences on a person's life and the actual psychological and physiological reality as experienced by the person (Ussher, 2000). However, the strengths of these two approaches lie in their attempts to

understand the transactional nature of interactions in shaping self and to implicate cultural, historical, structural and social forces in shaping people's social worlds. As such, I have used them in the production of data, and as analytical and explanatory tools throughout this thesis.

Both symbolic interactionism and social constructionism focusing as they do on human interactions, are interpretivist approaches. Their methodologies are similar, relying on interviews and on systematic observation of people acting and interacting in their own worlds to explore how and why they define the situations they act in (Charon, 2007), and how and why actions and behaviours position, shape, constrain, sustain or transform selfhood (Snyder, 2006). It is for these reasons that I chose an ethnographic methodology for this research, using methods which allowed me to capture the circularity of interactions and to tease out the consequences of such interactions for participants.

Further, the radical nature of social constructionism allows me to implicate the actions of others in contributing to the well or ill-being and type of Self-expression of those with dementia living in institutional care.

As these are both relativist, interpretivist schools of thought, I cannot claim an immutable understanding of the "reality" of participants' experiences. I can, however reference complex historical, social and cultural forces in shaping action and interaction. Although my findings can only be understood in a present context; reflecting the present social and cultural period, they will build

on the small body of knowledge about the social worlds of people with dementia living in institutional long-term care.

Conclusion

In this chapter, I have outlined the origins and assumptions of symbolic interactionism and social constructionism, and have used both approaches to highlight the reciprocal, co-construction of identity within social interaction. I have pointed to the value of both positions in grounding my research, and to their appropriateness, both in terms of theory and methodology in exploring the social worlds of people with dementia. Finally, I have positioned myself as a rebel, in social constructionist terms, by proposing that different interaction types of others contribute to well or ill-being and expressions of Self of people with dementia in institutional care.

In the following chapter, I introduce Kitwood's (1997) work on person-centred care and Sabat's (2001) work on selfhood in dementia; works which are central to this thesis. I follow this with a discussion of creativity as another means of facilitating person-centred interactions in the care of those with dementia.

Chapter 3: Personhood and self in dementia

Introduction

In this chapter, I present the central ideas on which this thesis is based. I introduce Kitwood's (1997) stance on personhood and person-centred care, which draws on ethics and social psychology, and I describe negative and positive aspects of interaction, which can either undermine or uphold personhood in people with dementia. I then describe Sabat's (2001) social constructionist approach to selfhood, and discuss philosophical and social influences on ideas of loss or maintenance of self, before briefly discussing the changing culture of dementia care. In the final section of this chapter, I discuss creative sessions as another possible way of facilitating person-centred interactions for those with advanced dementia.

Personhood

Personhood is a relatively new consideration in the care of people with dementia. It emerged through the work of Tom Kitwood and Kathleen Bredin (1992), who challenged the dominant biomedical paradigm, which conceptualised dementia in terms of neurodegenerative pathology, decline and loss. Within this paradigm, people labelled with the term "dementia" are in danger of becoming transformed from spouse, parent or friend to "wanderer" or "demented"; resulting in a significant undermining of their personhoods (Kitwood, 1997). Sterin (2002:8), writing from experience, reiterates this point by

describing how the label "dementia" robbed her of dignity and respect; as other people reacted to her in ways which ostracised her from normal interaction.

Kitwood's (1997:8) often cited definition of personhood 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.*

Although I take issue with Kitwood's idea of "bestowal"; for what is bestowed can also be taken away, this definition seems to encompass a status and a state of being. It could mean that personhood is accorded to the person with dementia in a one-way process, but that would be to deny the person with dementia the part she/he plays in relationships; whether it is reciprocal, giving or taking. Rather, this definition of personhood draws attention to the interdependence and interconnectedness of human beings, to our need for social relationships and to our positioning of others within relationships.

Kitwood (1997:45), who spent ten years observing care settings, interviewing formal and informal carers and working with people with dementia, charged the dominant medical paradigm with contributing to care practices that involved "bestialization, the attribution of moral deficit, warehousing and the unnecessary use of a medical model". He argued that people with dementia, who endure this type of care, are at risk of depersonalization; as their personhoods are consistently undermined. Kitwood (1997) suggested that depersonalization can occur through a dialectical interplay between neurological alterations in brain

function and exposure to "malignant social psychology"; resulting in the development of an involutionary interactional spiral and causing catastrophic psychological damage to people with dementia.

Kitwood (1990; 1997:46-47) systematically observed people with dementia in their own homes, in day hospitals and in residential care and identified 17 elements of interaction which, in order to highlight their pervasiveness in society and potential for psychological damage, he termed malignant social psychology. He describes these elements as:

- Treachery – using forms of deception in order to distract or manipulate people; or force them into compliance.

- Disempowerment – not allowing people to use the abilities that they do have; failing to help them to complete actions that they have initiated.

- Infantilization – treating people very patronizingly (or "matronizingly"); as an insensitive parent might treat a very young child.

- Intimidation – inducing fear in people; through the use of threats or physical power.

- Labelling – using a category such as "dementia" or "organic mental disorder" as the main basis for interacting with people and for explaining their behaviour.

- Stigmatization – treating people as if they were diseased objects, aliens or outcasts.

- Outpacing – providing information, presenting choices etc. at a rate too fast for people to understand; putting them under pressure to do things more rapidly than they can bear.

- Invalidation – failing to acknowledge the subjective reality of people's experiences, and especially what they are feeling.

- Banishment – sending people away or excluding them, physically or psychologically.

- Objectification – treating people as if they were lumps of dead matter; to be pushed, lifted, filled, pumped or drained; without proper reference to the fact that they are sentient beings.

- Ignoring – carrying on (in conversation or action) in the presence of people as if they were not there.

- Imposition – forcing people to do something, overriding desire or denying the possibility of choice on their part.

- Withholding – refusing to give asked-for attention or to meet an evident need.

- Accusation – blaming people for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation.

- Disruption – intruding suddenly or disturbingly upon people's actions or reflections; crudely breaking their frames of reference.

- Mockery – making fun of people's "strange" actions or remarks, teasing, humiliating, making jokes at their expense.

- Disparagement – telling people that they are incompetent, useless, worthless etc., giving them messages that are damaging to their self-esteem.

The term malignant social psychology does not always imply conscious or ill intent (except, perhaps, in the case of mockery); it is, according to Kitwood, part of our cultural heritage, and is often evident during everyday interaction. Kitwood (1997:48) suggests that the malignancy of interaction tends to increase in proportion to three factors: fear, anonymity and the differential of power. Thus, those with dementia who ignite fear in others, whose biographies may be unknown to caregivers and who are without power are most damaged by the elements of malignant social psychology.

Indicators of damage to personhood; as evidenced by ill-being, are: unattended sadness or grief, sustained anger, anxiety, boredom, apathy and withdrawal, despair and physical discomfort or pain (Bradford Dementia Group, 1997:5). To an uninformed or medically oriented observer, these indicators might be attributed to the process of dementia. However, in proposing a dialectical interplay between neurological impairment and a malignant social-psychological environment, Kitwood (1990; 1997) exposes the role that others (formal and informal carers) play in undermining personhood of those with dementia. I will explore this idea further, in the discussion of Sabat's (2001) approach to selfhood later in this chapter.

Exposure to disempowering care (Faulkner, 2001) may also lead to learned helplessness (Seligman, 1975), in which experiences of uncontrollable events

result in an expectation that future events will be uncontrollable as well. This expectation leads to lowered motivation and depressive affect (Faulkner, 2001), and may in part explain some indicators of ill-being noted above. However, Faulkner (2001) also showed that learned helplessness may be replaced by learned mastery in the presence of empowering care. These findings add further weight to Kitwood's (1997) proposition that the interactions of others are crucial in undermining or upholding personhood.

Kitwood (1997) suggests that, if personhood can be undermined by the negative interactions of others, it can also be upheld by the positive interactions of others. He talks of the cluster of five great psycho-social needs; for comfort, attachment, inclusion, identity and occupation that overlap and culminate in the central need for love. We all share these needs, but people with dementia, or other psychologically, emotionally or physically vulnerable people, require greater support from others in order to meet them. Like a flower, these needs require nurturing in order for the person to thrive, and their interconnectedness means that if one need is met or unmet it will feed positively or negatively into the other needs too (Kitwood, 1997:84).

Kitwood (1997:90-92) describes ten aspects of positive interaction (or positive person work) by which the person with dementia is drawn into the social world and by which this cluster of needs is met. They are:

- Recognition – in which people are acknowledged by name or through facial recognition and in which their uniqueness is affirmed.

- Negotiation – in which people are consulted about their desires and needs. This can have the effect of empowering them as some control over activities is handed back.

- Collaboration – in which people work together to achieve a shared aim and in which their initiatives and abilities are actively included.

- Celebration – in which the atmosphere is expansive, convivial and joyful. Divisions between people are broken down as all are caught up in the mood of celebration.

- Play – in which there is no goal, and spontaneity and self-expression take over.

- Timalation – in which interaction is non-conceptual and non-demanding but is sensual, reassuring and pleasurable.

- Relaxation – in which the pace is slowed down and intensity is lowered.

- Validation – in which the subjective truth of the person is acknowledged and in which empathic understanding is sought.

- Holding – in which a safe psychological space is provided for the expression of conflict, trauma, guilt or fear. The safety of this space rests on the knowledge that whatever is expressed will pass and some resolution will follow.

- Facilitation – in which people are enabled to do what they would otherwise have been unable to do; by the provision of those parts of the action that are missing.

Other types of interaction are possible, in which the person with dementia takes the lead and the carer offers an empathic response. Kitwood gives two examples:

- Creation – in which the person with dementia spontaneously offers something to the social setting, for example beginning to sing or dance.

- Giving – in which the person with dementia expresses concern, affection or gratitude, offers to help or presents a gift to another.

Person-centred care

These elements of positive person work (positive interaction), by drawing people with dementia into the social world, meet their psycho-social needs for comfort, attachment, inclusion, identity, occupation and, ultimately for love. This is person-centred care in practice and is based on the principle that the personhood of individuals should be and can be preserved through an ethic of respect, which is demonstrated by positive interaction within relationships. Brooker and Surr (2005:13) provide a useful definition of person-centred care, which encompasses a philosophical stance and a way of understanding and working with people with dementia:

> *Person-centred care values all people regardless of age and health status. It is individualised, it emphasises the perspective of the person with dementia and stresses the importance of relationships. The primary outcome of person-centred care for people with dementia is to maintain their personhood, in the face of cognitive decline.*

Person-centred care serves to uphold personhood and nurture well-being – indicated by combinations of assertiveness, bodily relaxation, sensitivity to the emotional needs of others, humour, creative self-expression, taking pleasure in some aspects of daily life, helpfulness, initiating social contact, affection, self-respect, expressing a full range of emotions and acceptance of others who have dementia (Bradford Dementia Group, 1997:5). Person-centred care incorporates acknowledgement of people's biography and identity, it recognises their agency and autonomy, and it promotes communication, interaction, inclusion and occupation. Here, the person is "seen first", and dementia is "seen second".

A person-centred approach requires ongoing critical self-reflection of those who try to work within its philosophy. It also requires energy, motivation, sufficient resources, staff support and, for those who are not yet aware of its principles, training and reinforcement. Packer (2000a) calls for the same values of person-centred care to be applied to care workers in order that their own personhoods are nurtured and their practice is enhanced. However, McCormack (2004:37) cautions against chasing after the ideal of person-centredness. Instead, he advocates striving for "a constant state of 'becoming more person-centred' in our practice".

Person-centred care is not easy to sustain; neither in daily relationships nor in the care of people with dementia who will express a wide variety of needs, emotions and responses. The poor status of care work, lacking in glamour and professional prestige along with care workers' lack of political influence (Innes,

2002) may impede a move towards a more person-centred approach. Indeed, Packer (2000b) reflects that, with inadequate staff training and support, a person-centred approach may be difficult to achieve, while Brooker (2004) contends that, without changes in policy and practice, staff selection or national frameworks, services will not achieve their person-centred goals. Further, Bond et al. (2004) contend that dominant ageist, sexist, racist and disablist cultural values serve as a barrier to achieving person-centred care.

It was this gap between theory and practice and a recognition of the social constraints to achieving person-centred care, which drove me to explore another way of developing person-centredness in dementia care; creative sessions, which I will explore in the final section of this chapter.

Person-centred language

In caring for people with dementia, a knowledge of theory is not enough; practitioners must develop a new person-centred language to describe aspects of dementia. Fazio (2001) argues that to be truly centred on the person we must always speak about and treat the person as just that – a person. We need to use language that helps lead to person-centred care, not limit it. Often the words that caregivers use contradict the way they say they want to act, for example, the use of "victim" or "patient" separates the caregiver from the actual person in the relationship. Paradoxically, even within person-centred literature, reference is made to "dementia victim" (Williams and Rees, 1997:317). Here, practitioners may "talk the person-centred talk but do not walk the person-centred walk" (Packer, 2000b:19).

There are those, however, who appear not even to talk the person-centred talk and who assume notions of loss in their discourse on dementia. Davis (2004:377) urges that "the seductive nature of Kitwood's arguments should be resisted so that the debate can continue as to the status of people with dementia". Kitwood "must allow for a loss of personhood". Davis (2004:378) also argues that Kitwood's insistence, that personhood can be maintained through positive interaction, prevents relatives from initiating the grieving process as dementia progresses. As the person's life draws to a close, relatives:

> *… would do better to be removed from this final process. For then they might be allowed to determine, with courage, that there is nothing left of their past together.*

Hodder (2004:335) appears equally pessimistic about the impact of dementia on personhood. She writes of her mother:

> *What is so tragic with Alzheimer's is that as far as the sufferer is concerned, there comes a point past which the wheel of life grinds to a complete stop and there is nothing more to be gained…there are no more lessons for her to learn, pleasures to be sought or insights to be gained. Her experience has become part of the cycle of death, where loss builds upon loss until there is nothing left for her to lose.*

Ideas such as these, which question a continuing personhood and which perpetuate notions of loss and despair, do little to foster an ethic of respect and

to nurture the personhood of those with dementia. As Kitwood (1997:16) points out:

> *If uniqueness has faded into a grey oblivion, how far is it because those around have not developed the empathy that is necessary, or their ability to relate in a truly personal way?*

Contrast this with the description by Clarke (2004:22-23), who used coma work to communicate with her mother in the very end stages of dementia when all verbal communication had ceased:

> *Our finger meetings were sometimes like little waves on a smooth sandy beach in fine weather – a very gentle to and fro, with my voice and occasionally hers also "conversing": we made sounds, having no need of words. ..She has, it turns out when I really pay attention, several ways of expressing herself. And the miracle is that in so doing she once again engages with me.*

Here, Clarke accords personhood to her mother; using elements of positive person work – recognition, collaboration, relaxation and facilitation, and by these means, she draws her mother back into the social world for a short time.

Summary

In this section, I have defined personhood in relational terms as encompassing an accorded status and an emerging state of being. I have discussed Kitwood's (1997) proposition that interactional elements of malignant social psychology and positive person work can undermine or uphold personhood. I have

suggested that person-centred care is not easy to maintain, and have pointed to concerns about its applicability without adequate staff training and support.

In the next section, I will discuss Sabat's (2001) social constructionist position on selfhood. I will discuss differing understandings of self; particularly exploring literature which subscribes to loss or maintenance of self and I will map these differing positions onto philosophical and social understandings of selfhood in order to identify the origins of such differing way of conceptualising self.

Selfhood

Harré (1983:203), taking a psychological social constructionist approach, talks of people's "sense" of personal identity; how people experience their unique selfhoods. According to him, a necessary condition for a sense of personal identity is that individuals should be self-conscious: they should be aware of their experiences as constituting a personal unity. "Consciousness as knowing" involves both knowing what one is experiencing and knowing that one is experiencing it (Harré, 1983:28). To have a sense of self is to have a sense of one's location as a person. Each person is a unique embodied being; having a distinct history and possessing unique attributes and capacities.

Within the field of dementia care, the Selfs framework evolved with the work of Sabat and Harré (1992), who used social constructionist theory to argue against the dominant assumption of loss of self as dementia progresses. They described a singular self[1]: expressed through first person indexicals "I", "me", "mine" and "myself", and selves[2]: our personae and ways of behaving that are

contingent on the cooperation of others[1]. They used two in-depth case studies to show how self[1] remains intact despite severe cognitive decline and to demonstrate that "the threatened disappearance" of selves[2] is not directly linked to the disease process, but to the behaviours and reactions of others (Sabat and Harré, 1992:459).

Their approach was reworked and extended, using social constructionist theory (Sabat and Collins, 1999; Sabat, 2001), to include three discursive aspects of Self (Selfs 1-3), which I use in this thesis. Sabat's detailed descriptions of Self-expression provide a useful framework for exploring visual and verbal expressions of Self of people with dementia in long-term care. His work implicates the actions and attributions of others; informal and formal carers, members of the public etc. in positioning people with dementia (Sabat et al., 2004; Sabat, 2006) and in contributing to construction or deconstruction of their selfhoods (Sabat and Harré,1992). I firstly describe Sabat's Selfs 1-3 before discussing literature on self in dementia.

Selfs 1-3

Self 1 is the Self which expresses first person indexicals "I", "me", "myself", "mine" or "ours". This aspect of Self reflects the fact that each person has one single point of view in the world. By using first person indexicals, we take responsibility for our actions, we locate for others our experiences and feelings and we tell stories about ourselves. Self 1 can be expressed verbally, for example: "That's mine" or "I like that" and also through visual expressions which

---

[1] Sabat and Harré (1992) only used two expressions of self; self[1] and selves[2]. The Selfs 1-3 framework came later with Sabat and Collins (1999) and Sabat (2001).

would signify identification with oneself, for example, reacting to one's name being called, taking possession of an object or reacting to protect oneself. Sabat (2001) suggests that Self 1 remains largely intact in people with dementia, even with severe cognitive decline.

Self 2 comprises one's physical, mental or emotional characteristics and attributes, and also one's beliefs and desires about them. Some Self 2 attributes have long histories, for example, past achievements, while some have more recent ones, for example, increasing frailty accompanying an illness. A valued or desired Self 2 attribute can be reclaimed through affirming interaction with others. Positive expressions of Self 2 could include articulating awareness of characteristics and attributes: "I can do that" or remembering achievements from long ago. Positive visual expressions of Self 2 could be admiring oneself in the mirror or expressing pride at an achievement. Self 2 can also be expressed in negative terms: "I can't do that"; "I'm no good", by reluctance to engage in something or by becoming upset, frustrated or angry at one's inabilities. Sabat (2001) suggests that Self 2 remains largely intact with cognitive decline, although it is vulnerable when others view disabilities caused by dementia as being attributable to the person rather than the illness. This, malignant positioning, contributes to a loss of self-worth and will be discussed further below.

Self 3 is the publicly presented aspect of ourselves; the roles we take on and the appropriateness with which we behave in social situations. We have many Selves 3, which we express in different social circumstances; parent, friend,

professional, carer or cared-for. Each Self 3 requires different ways of behaving and carries with it different expectations. Expressions of Self 3 could be enacting a familiar role such as wife or husband, showing regard towards another, being protective, being gracious or showing agency (Sabat and Collins, 1999). Self 3 is constructed, sustained, nurtured or changed through interaction with others and is more vulnerable to damage than Selfs 1 and 2. For example, one cannot construct the Self of a loving spouse if one's husband or wife does not accord one the status of spouse (Sabat, 2005). Thus, others' positioning of people with dementia help to define, strengthen or weaken their social identities (Sabat, 2002; Sabat et al., 2004). Negatively positioning people with dementia based on physical or cognitive difficulties is to position them in a potentially malignant way (Sabat, 2006). This renders people with dementia particularly vulnerable in social situations; as they depend on the affirmation and co-operation of others to co-construct (Snyder, 2006) and support a valued Self 3.

Using Selfs framework in research

While he claims a social constructionist foundation to his work; in that selfhood is constructed through interaction with others, Sabat's (2001) work also resonates with symbolic interactionist ideas on the circularity of our interactions as we strive to find meaning in our social worlds. His work has been pivotal in exploring and arguing for persistence of Self, even with serious cognitive decline, but particularly in implicating the interactions of others in causing damage to selfhood of people with dementia. However, despite increasing interest in exploring self of people with dementia, there have been few studies

which use Sabat's Selfs 1-3 framework to explore self, as shown in this overview of the literature below.

Researchers have used different conceptualisations of self and different methods for assessing self in dementia. Some have explored autobiographical memory and continuity of identity (Addis and Tippett, 2004), self in discourse (Small et al., 1998; Snyder, 2006), and narrations of self through life stories (Usita et al., 1998). Others have explored managing a sense of self in early Alzheimer's (Pearce et al., 2002), managing threats to self (Clare, 2003), preservation of self following diagnosis (Beard, 2004) and role-identity in people with dementia in long-term care (Cohen-Mansfield et al., 2000). Klein et al. (2003) taking a quantitative psychological stance, studied preservation of personality traits in advanced dementia, while Cotrell and Hooker (2005), also carrying out a quantitative psychological study, assessed possible selves in people with mild to moderate Alzheimer's disease.

While several of the researchers cited above refer to Sabat's work, only three studies have used the framework in analyses of Self-expression. Small et al. (1998) drew on Sabat and Harré (1992) to explore for verbal and non-verbal expressions of self[1] and selves[2]. They found that self[1] and selves[2] were indexed in different ways, even with severe cognitive decline. They also pointed to the ways in which staff positioned participants who had dementia; in relation to their perceived dependency, resulting in resistance by participants.

Tappen et al. (1999), also citing Sabat and Harré (1992), explored evidence of persistence of self in 21 nursing home residents with moderate to severe dementia. They found, in their tape-recorded interactions, frequent references to the first person indexical; indicative of an awareness of present self. However, their study was limited in that they only explored self[1], which Sabat and Harré (1992) concluded does remain intact even with severe cognitive deterioration. Further, their reliance on tape-recorded interviews meant that they were unable to explore for visual expressions of self.

Snyder (2006) described verbal expressions of Selfs 1-3 within support groups for people with dementia. She showed how group facilitators acknowledged and affirmed Self 2 and how, by validating social personae, they co-constructed with participants their Self 3. Critically, Snyder's work, by focusing on talk, omits visual expressions of Self; which may be the sole means of expression for those without verbal communication.

As all but the latter study used the earlier work on self, there is a need to update this body of research; to explore expressions of Selfs 1-3 as laid out by Sabat (2001). Drawing on symbolic interactionism and social constructionism, I aim to do this by using his Selfs 1-3 framework to explore the responses of people with dementia in institutional care to staff interactions in terms of their verbal and visual expressions of Self. I will argue that the value of Sabat's framework lies in its intuitive applicability in practice, requiring observation of people with dementia, rather than measurements or interview schedules, as used in some

of the studies cited above. Thus, his framework can be applied by practitioners in their everyday care of people with dementia.

Dementia and persistence of self?

In this section I will try to explore the different understandings of self, and identity within the literature and what this means in terms of conceptualising the maintenance or loss of self in people with dementia. Concepts such as "self", "personhood" and "identity" are often used interchangeably and the ways we choose to use them can reflect our philosophical and spiritual approach to life (Coleman and Mills, 2001) and thereby our understanding of dementia.

A dominant way of viewing dementia, in terms of neuropathology, decline and loss of identity, has stemmed from the philosophical writings of Descartes (1640). I will firstly outline the Cartesian dualism debate, in order to place subsequent sub-sections in context. Then I will discuss differing positions on loss or maintenance of self.

The Cartesian debate: "I think, therefore I am"

Descartes (1640) claimed that we cannot know our own selves, nor can we know anything about the external world of objects through our bodies or through bodily sensations; for, because the senses can be fooled, they are unreliable as sources of knowledge. The only reliable source of knowledge, both of the external world and of the self, is thought. It is the mind as distinct from the body that makes a sense of self possible. This has been an influential proposition, shaping discourse and assumptions on the status of people with serious cognitive disability and fuelling ideas on loss of self in dementia.

Burkitt (1998) rejects the influential Cartesian idea of two fundamentally distinct realms: mind and matter. This, according to Burkitt (1998), is a persistent notion in western society, such that if a person is deemed to be "brain dead" or in a "permanent vegetative state" many people would question whether he/she should be kept alive. For, following Descartes' argument, once a person is no longer able to think, reason or reflect on her own existence then she has in effect died and all that remains is a shell. Burkitt (1998) agues that there is no such "thing" as a mind, which exists as an entity separate from the body. Instead he argues for a position that assumes one (albeit complex) entity. What we call "mind" can only exist because we have bodies through which we experience and act on the world, thus, all knowledge is situated and embodied.

In this understanding, the body is central to identity and personhood. As Rentsch (1997:267) observes, "The body is not a shell in which we are hidden. It is not the outside of an inside… rather, the human body is the middle of our dynamic reality". Kontos (2005:567) reinforces this point:

> *Understanding selfhood as embodied can enrich the discourse on Alzheimer's by illuminating dimensions of personhood that persist despite the ravages inflicted by neuropathology. Personhood persists as an embodied dimension of human existence and, as such, must be embraced in dementia care.*

In opposition to Cartesian thinking then, selfhood does not simply reside in the mind but within the slowly changing nature of the singular body, within the relatively stable aspects of a person's character, within characteristics and

attributes and within the personae the person takes on and discards. I will discuss these ideas following the next sub-section.

Loss of Self

Three interconnected ways of thinking emerge from the literature, which appear to contribute to assumptions of loss of self held by practitioners and carers. These are the deficit model of understanding dementia, the role of social factors and the focus on a past self. These socially constructed ways of conceptualising self continue to sway some practitioners and carers towards assuming that loss of self is inevitable as dementia progresses. This position can be catastrophic for the person whose cognitive abilities are declining; as described by Sterin (2002), who talks of the way in which the term "demented" positioned her as "without a mind"; socially identifying her as not being fully human and heightening the isolation she experienced.

The deficit model

The deficit model, being grounded in the biomedical understanding of dementia, conceptualises dementia in terms of cognitive, social and emotional decline. This strongly influences the work of Fontana and Smith (1989) who talk throughout of the "victim", of the "unbecoming" of self and of the self becoming "slowly unravelled" as the disease progresses. Ronch (1996:27) suggests that loss of self is a tragic reality of Alzheimer's disease "victims", postulating that "loss of self is the essential existential impairment in AD". Cohen-Mansfield et al. (2000:381), talking in a similar manner, suggest that dementia "destroys the brain and confuses the mind; it disintegrates the self and degrades one's dignity and soul". Davis (2004:378) talks of the "violence that dementia does to the

substance of the person" and he calls for relatives to be allowed to mourn the loss of the person in the final stages of the disease. Cohen and Eisdorfer (1986:22), while looking for ways to transcend Alzheimer's disease, still suggest that "the victim of Alzheimer's disease must eventually come to terms with….the complete loss of self". In a quantitative study, Addis and Tippett (2004) linked identity with personal semantic memory and personal incident memory[2] and concluded that their participants with Alzheimer's disease experienced changes in the quality of their identity. While assuming a less negative approach, they too subscribed to the deficit model of dementia.

The presumed loss of self, which is implicit in the deficit model is, according to Kontos (2003), more the product of philosophical inheritance than neuropathology. There are clear parallels between these ideas on loss of self and the legacy of Cartesian thought.

Society's role in perpetuating ideas of loss of self in dementia

The historical division between acute and chronic sick, and the resultant differences in status accorded to these different groups of people, has made medicine unwilling or unprepared to respond to the needs of an ageing population (Phillipson, 1982). As seen in chapter 1, bio-medical or gerontological approaches to the ageing and old continue to be influenced by ageist, cultural bias; seeing old age as a problem (Haveven, 1995). Ageism (Bytheway, 1997) contributes to the distancing (Andrews, 1999) of healthy people from the aged, and particularly from those with dementia.

---

[2] Personal semantic memory is memory for personal information that is not event based, for example names of friends or where one went to school. Personal incident memory is a component of autobiographical memory and is a memory of a specific personal event.

Strauss (1959:79) linked loss of identity with the process of "status-forcing" whereby society thrusts individuals into different identities according to social rules and assumptions. Further, the attributions others ascribe to people with dementia will influence how they are perceived and received (Laing, 1961). These ideas resonate with the work of Sabat et al. (2004) who, in a case study of a woman with Alzheimer's disease, describe malignant positioning; in which she was positioned negatively by her family and care staff because of her cognitive difficulties. Explanations of her behaviour, based on her inabilities were extended to abilities that were not compromised by Alzheimer's, resulting in much of her behaviour being explained in dysfunctional terms or not noticed at all. Thus, her difficulty with word-finding resulted in her being positioned as unable to communicate, and because her intentions were misunderstood, she was positioned as irrational and was disempowered. This example, resonating with Rosenhan's (1973) experiences cited in chapter 2, shows how the attributions of others, based on misunderstanding, misinterpretation and assumptions of decline resulted in a loss of her social identity. This, as Kitwood (1997:51) argued, can result in an "involutionary spiral" of decline.

Socially constructed ways of thinking can also influence how caregivers understand dementia. For example, Traphagan (2002), who studied the cultural construction of "senility" or *boke* in Japan, identified a strong moral component in the understanding of dementia, which linked idleness with disintegration of the mind/body complex. Here, *boke* is attributed to the individual who is then held responsible for the onset of the condition. In the US, Hinton and Levkoff (1999:461) found that, within the narratives of carers, dementia-related changes

were constructed as "signs of deteriorating brains and of diminishing selves". They suggest that these narratives reflected a "powerful culturally shaped meaning of Alzheimer's" in contemporary western society, which influences both the understanding of dementia and the coping strategies of carers.

Sweeting and Gilhooly (1997) identified an extreme form of coping in which some relatives of people with dementia coped by detaching emotionally from them, behaving towards them as if they were socially dead. This is exemplified by Hodder (2004:335) who physically withdrew from her mother in the later stages of her Alzheimer's: "losing Mom to Alzheimer's is no different than losing her to death". These distancing coping styles reflect influences from both the deficit model and from culturally influenced and socially constructed understandings held by those involved in the care of people with dementia and by wider society.

Past self as a signifier of identity

Hodder's (2004) difficulties in trying to identify solely with her mother's past self, instead of seeking out new ways to identify with her present self caused her to eventually withdraw from her mother. The emphasis on hanging on to a past self is a recurrent theme in the discourse of carers. For example, Orona (1997:193) discusses at length how relatives tried to find ways (through ritual and memory keeping) to "maintain vestiges of the person as known". Ultimately, though, the changes noted by caregivers in the identity of people with dementia, lead them to accept the "loss of the person"; to regard the person as "the shell of someone we once knew" (Cohen and Eisdorfer, 1986:260) or to refer to the person as a "vegetable" (Gubrium and Holstein, 1999). Familiar social roles are

withdrawn from the person with dementia leaving him/her with only the roles of patient and dementia sufferer (Bender and Cheston, 1997). Friedell (2002:359), speaking from personal experience, laments the loss of his past self and talks of the horror of the slow disintegration of self: "vital active living feels more remote, as does the past when I used to be 'normal'".

Maintenance of self

The literature supporting maintenance of self holds that to lose cognitive abilities or emotional qualities that have previously defined one's sense of self does not mean that a sense of self no longer exists (Snyder, 2001).

Within the literature, which endeavours to "resuscitate the humanity" of people with dementia (Herskovits, 1995:154), the language differs; the "victim" or "sufferer" has become a "person" or "individual" (Downs, 1997). Here, the foci are on the existence of a core self and on the identity work that people with dementia do themselves, both as individuals and within relationships, in working through changing conceptions of self. I will discuss these two points below.

Core or present self

Addis and Tippett (2004) caution that practitioners and carers must be aware that objectively attributing loss of identity to people with dementia may deny them their core sense of self, which they may continue to experience. Sherman and Webb (1994) suggest that self should be seen as an ongoing process rather than a product; it is continuously being created and re-created through interaction with family, friends and strangers. A present self is defined in relation to core values (Harris and Sterin, 1999) which are consistent with the past. Yet

self is also irreplaceable (Rentsch, 1997). This is exemplified by Bryden (2005:162) who, speaking from experience, arrives at the end of a journey of discovery with the recognition that: "I am no longer the outer layer, the outer mask, of who I used to be…I am who I am." This aspect of self: the spiritual; transcendent; experiential; embodied self just is, and will be until we die. It does not rely solely on memory, communication, psychological continuity or cognition. Instead, Bryden (2005) sees herself, not only as a spiritual being but also as a situated, embodied agent (Hughes, 2001). Kontos (2004:846), in arguing for a continuing selfhood, proposes that:

> *If we could shift the discourse on selfhood in Alzheimer's disease towards a greater recognition of the way humans are embodied, it would critically challenge the widespread presumption of the loss of agency with cognitive impairment. It would do so by disentangling selfhood from the cognitive categories upon which long-standing notions of selfhood are presumed, and it would ground selfhood in corporality.*

The self "is understood to reside in the ways that the body moves, perceives and behaves" (Kontos, 2003:166-167), thus, it persists despite cognitive decline.

Identity work within relationships

In the previous chapter, I noted that self-identifying work occurs throughout life within interaction (Hadden and Lester, 1978). Thus, as the body changes through age and illness so too do our self-conceptions (Kelly and Field, 1996); requiring a reconceptualising and reconstructing of the meanings that the body holds for our self (Biggs, 1997). Work to maintain and to present one's self

continues to occur as dementia progresses (Sabat and Collins, 1999). Clare (2003) proposes that, early on in dementia, managing a sense of self is achieved through complex reiterative processes, which fall on a continuum between self-maintaining and self-adjusting. There exists a tension between attempts to protect the self from threat and attempts to engage with potential threat in order to reintegrate the resulting experience into the self. Pearce et al. (2002) also suggest that sense of self is managed by balancing the tension between wishing to maintain the prior sense of self while needing to reappraise and reconstruct a new sense of self in the light of changes in cognitive, environmental or social factors. These processes, which take place within nurturing relationships, support the idea that personhood is best sustained within relationships (Kitwood, 1997).

Surr (2004) suggests that self in the person with dementia should be considered as a complex interplay between a number of social and biographical factors; including interpersonal relationships, the social context, opportunities for and abilities to communicate aspects of self and individual coping styles and strategies. Of particular importance is the role that deep bonds with other people can play in supporting self, whether they be family or formal caregivers. Relationships which offer opportunities for attachment, positive regard, care, nurturance and recognition will enable the person with dementia to project and experience a desirable self. Goyder (2001) talks of storying; of how people, even with advanced dementia, in telling stories and fragments of stories, tell of themselves. Her relationship with her patients deepened as she realised the

power of their stories in telling of self. Thus, within relationships, their valued social personae were "co-constructed and maintained" (Snyder, 2006:270).

While these accounts of management and maintenance of self rely on the communicative abilities of people with dementia, their findings can be less easily applied to people with increasing communicative difficulties. As communicative ability diminishes over time, this must not be interpreted to mean that a person no longer has subjective experiences of dementia (Snyder, 2001). Instead, an appreciation of how the lived body continues to be involved in the world, even as words fail, becomes crucial (Phinney, 2002; Phinney and Chesla, 2003).

It is now accepted that communication with people with advanced dementia is possible (Killick and Allan, 2001), but as caregivers often fail to attend properly, hear or recognise communicative attempts by people with dementia (Innes and Capstick, 2001), their attempts at communication may be missed. Li and Orleans (2002) found that, through close observation, they were able to discern the individuality of participants with limited verbal communication. They advise that "we must interpret their behaviour not by our standard, but by their being" (Li and Orleans, 2002:242). Gubrium and Holstein (1999:531), who analysed the discourse of family carers, noted that some carers resisted dominant discourses of loss by looking for even the smallest signs of response: "..even a faint smile or sparkle in the eyes can be said to mark the continued personhood" of a person with dementia. Sabat (2005) and Kitwood (1997)

would go further and argue that it is through the co-operation of others, within social interaction, that selfhood and personhood endure.

Hubbard et al. (2002a) studied non-verbal presentations of self and noted that frailer people with dementia, acting in the context of shared meaning, used body posture to present particular personae, for example as active listener. They also used non-verbal behaviour to communicate to themselves. For example, a man was noted rubbing his walking stick, possibly to remind himself that it was beside him. The many incidents of non-verbal communication identified by Hubbard et al. (2002a) suggest that frail people with dementia will work to remain part of the communicative world and to preserve their sense of self. The onus is on us, as individuals and as a society, to facilitate maintenance of self by what means are available to the person with dementia.

Summary

In this section, I have explored ideas on loss or maintenance of self in people with dementia. I have pointed to the influence of Cartesian dualism as contributing to ideas on loss of self. I have also pointed to the deficit model of understanding dementia, to deeply embedded social assumptions and understandings and to a focus on a past self as further contributing to ideas of loss of self.

Those who subscribe to maintenance of self, focus on an enduring core self and stress the importance of identity-maintaining work within relationships as contributing to maintenance of self. This is the stance I take.

Linking Kitwood and Sabat

Having laid out the two key contributors to my research: Kitwood (1997) and Sabat (2001), I will now integrate both sets of ideas for this thesis.

The Selfs 1-3 framework suggests an experiential and expressive Self. It illustrates how we locate ourselves to others, how we acknowledge and celebrate our attributes and characteristics and how we take on and enact social roles. These aspects of Self (particularly Selfs 2 and 3), require the validation, recognition and co-operation of others. In dementia care, this requires the application of the principles of person-centred care; specifically, the application of the elements of positive person work, such as recognition, validation, facilitation and negotiation. Thus, through experiencing positive person work within interaction, people with dementia can express Self and maintain their selfhoods.

Conversely, interactional elements of malignant social psychology, such as disempowerment, invalidation, objectification or ignoring, malignantly position people with dementia as without a valued selfhood: without valued characteristics, attributes or roles. Within such positioning, expressing a desired or valued Self will become increasingly difficult, and may be impossible, resulting in an involutionary spiral of cognitive and psychological decline (Kitwood, 1997).

By integrating the person-centred and selfhood approaches, I hope to develop a fuller picture of the social worlds of people with dementia in institutional long-

term care, with particular reference to how interaction types influence well-being and Self-expression.

From old to new culture of care

Kitwood (1997:135) compared the "old culture" of care, which emphasises medical authority, pathology, stages of decline, warehousing and functional interaction with the "new culture" of care, which emphasises interdependence, respect, biography, emotional expression and positive interaction as healing components of care. While I am not proposing that all those who subscribe to the "loss of self" position are working within all the assumptions attributed to the old culture of care, the legacy of this culture (as proposed by social constructionism) is such that its historical and institutional practices are deeply embedded, often unquestioned and difficult to shift. Those who already practice within the new culture of care must encourage a move away from associating dementia with tragedy and loss, "rather we must seek opportunities for the human spirit to emerge" (Woods, 2001:16). Kitwood (1997) challenges us to reconceptualise dementia and dementia care, to bring compassion to our care and, ultimately, to reclaim people with dementia as sentient social beings.

However, the rise of the psycho-social model of care advocated by Kitwood and others must also encompass all that is good in the medical understanding of dementia, such as managing pain or anaemia, which may exacerbate cognitive difficulties. For as Cox and Watchman (2004) suggest, as both the medical and the psycho-social models touch on important areas that the other omits, practitioners and carers should draw on the best from both approaches in order to provide care that is as comprehensive as possible to people with dementia.

While the new culture of care, with its emphasis on upholding personhood (and, I would argue, nurturing Self) through positive person work, is what we must strive for, its aims are difficult to achieve without ongoing training and mentoring. Even then, some practitioners have questioned its feasibility, as discussed above. How then, can we strive towards person-centredness in dementia care? In the next section, I suggest the creative process as a means for facilitating a type of interaction, which might, more easily facilitate person-centred care; thus promoting well-being and Self-expression of people with dementia.

Creative sessions to promote person-centred interactions?

There is no universally accepted definition of creativity. It has been variously debated as emanating from the divine, from inspiration, from madness, from an intuitive genius or from the life force inherent in life itself (Kneller, 1965). Kneller (1965:18) defines creativity as: "the discovery and expression of something that is both new to the creator and an achievement in its own right". Hauser (1974:23), while focusing on the sociology of art, talks briefly of artistic creativity as being the "will to expression". Rogers (1954:139) talks of the "emergence in action of a novel relational product, growing out of the uniqueness of the individual on the one hand and the materials, events, people or circumstances of his (sic) life on the other". Coming from a psychological position, Rogers (1954) argues that people's motivations for creativity are to achieve actualization; to realise their potentialities, to express, to develop, to mature and ultimately to enhance the self. This motivation, according to Rogers, exists in every individual and awaits only the right conditions for its expression.

Messman (2004) seems to capture these multiple ways of conceptualising creativity by describing it as encompassing originality, imagination, inspiration, ingenuity, inventiveness, resourcefulness and vision.

In this section, I will discuss the creative process in relation to the American and British art therapy fields before looking at claims for therapeutic benefits of creative sessions; such as improvements in well-being, heightened communication and expression of self. Finally, I will highlight shortcomings in much of the literature on creativity and dementia; in terms of its conceptualisation, methodology and analysis.

Art as therapy

American art therapy literature sees the creative process and its product as formal psychodynamic diagnostic and therapeutic tools. The goals of art therapy are to strengthen the sense of self through personal accomplishment, to allow the release of pent-up emotions, to provide verbal and visual means of communication, to bring people out of isolation into the camaraderie of a group setting and to stimulate reminiscence. Ulman (1975a:13) suggests that art therapy is "a way of bringing order out of chaos". It is a means for discovering both the self and the world, and for establishing a relation between the two. It provides the meeting ground between the inner and outer worlds of the person by means of structured creative tasks (Denny, 1975).

However, the emphasis on "victim" (Fontana and Smith, 1989) or the "patient" (Wald, 1983) within American art therapy literature suggests that it follows biomedical and stage models of dementia with its connotations of loss of self

and decline (Jenson and Wheaton, 1997; Baker, 2004). Fontana and Smith (1989:45), for example, describe how, for a person with dementia:

> *The self has slowly unravelled and 'unbecome' a self, but the caregivers take the role of the other and assume that there is a person behind the largely unwitting presentation of self of the victims, albeit in reality there is less and less, until where once there was a unique individual there is but emptiness.*

Further, they suggest that friends, relatives and staff "protect and speak for the victims and use many devices to diffuse their misconduct" (Fontana and Smith, 1989:42). Jenson and Wheaton (1997:178) emphasise the loss which accompanies dementia and suggest that the person "afflicted with Alzheimer's disease becomes merely a shell of the former self". This, they suggest is reflected in the fragmented representations within their drawings. Goldman (2004:207) suggests that Alzheimer's is:

> *…of greater magnitude than physical death, for it is a death of a human's spirit; his/her very soul.*

The positioning of people with dementia as losing their selfhoods is a recurrent theme in the American art therapy literature and is contrary to the person-centred approach to dementia care as advocated by Kitwood (1997).

Wald (1983:59) who is cited many times in contemporary American art therapy literature also suggested that volunteers must be on hand to "watch for anyone who may attempt to eat or drink the art materials". She also suggested that

those at risk of ingesting materials should be "kept aside at another table looking at art books". Further, a "high functioning patient may regress to primitive behaviour at any time, so one must be alert". There are many elements of Kitwood's (1997) malignant social psychology evident in Wald's work, which if followed unquestioningly, potentially expose the person with dementia to banishment, surveillance, imposition, disempowerment and infantalization, which, it could be argued, actually undermine the goals of art therapy. Indeed, Hellen's (2000:37) suggestion that the use of "therapeutic fibs" might be appropriate in interaction with people with dementia highlights the patronising nature of much American art therapy literature.

Art in therapy

In the United Kingdom, art provision is increasingly viewed from a person-centred perspective (Kitwood, 1997) and seen more in terms of the value that activities have in facilitating communication, interaction and self-expression (Lloyd and Papas, 1999); in which trust, warmth, positive regard and empathy are employed by the therapist/artist (Mottram, 2003). Here, the therapist/artist observes the art-making process and attends to the process as additional sources of communication within the session; in which thoughts, emotions and interactions can be expressed safely. Leslie (2001), who described her work with people with dementia, suggests that the process of creation seemed to be more important than the product; as seen in the atmosphere of calm, which descended on participants as they painted. Wood (2002) suggests that the aim of the art therapist is to achieve a meaningful connection both in relation to people with dementia and in their art-making. Connection is achieved when communication takes place between the person and the therapist and

"something is understood and insight or a sense of relief transpires" (Wood, 2002:214). Similarly, Wilks and Byers (1994) stressed the role of a therapeutic relationship between the therapist and people with dementia in facilitating the creative process. Wood (1998a) suggests that, in giving people freedom to use art materials in whichever way they wish, a sense of control is provided. This is especially valuable for those with dementia who have little control over large areas of their lives. Osler (1988) talks of a reduction in anxiety and an increase in confidence that occurred in a man with Alzheimer's disease who took part in art sessions. He would arrive at each art session anxious, uncertain and needing reassurance but as the session progressed, he would begin to work independently with increased concentration and enthusiasm. However, as with many reports of this kind, Osler (1988) does not present a sufficiently detailed methodology or description of analysis (see also Harlan, 1993; Sterritt and Pokorny, 1994; Wilks and Byers, 1994; Jenson and Wheaton, 1997; Hellen, 2000). Indeed, I support Marshall and Hutchinson (2001) who, in their critique of research in the use of activities with people with dementia, conclude that much research is subjective and interpretive and has design and measurement weaknesses. In contrast, I aimed for a methodology, which would provide qualitative insight along with structured frameworks for assessing changes in well/ill-being and for identifying expressions of Self, as discussed in the next chapter.

Creativity as promoting well-being

McNiff (1994:15) talks, within the context of a hospital, of the person's soul suffering acutely. The soul encompasses the existential, individual, vital nature of people, but in western philosophy, it has been abandoned in favour of the

body. He argues that practitioners have "given over the care of the soul to medications, institutions and a host of procedures that continuously undermine its dignity". Indeed, the suffering experienced by people with dementia is reiterated by Marshall (2001), who argues that those who move to long-term care are required to make major adjustments in their lives, as they enter into a mode of living which most of us would find intolerable. From living in a familiar environment, surrounded by familiar possessions and people, they find themselves living and suffering in a strange environment filled with strangers and strange ways. For McNiff (1994), the process of caring for the suffering soul takes place through the creative imagination; through painting together, meditating collectively on the images and through the communication that the images evoke. Chaudhury (2003) talks of tapping into people with dementia's long-term memories by using their line drawings to stimulate recall of their own homes. This allowed them to connect with their personal past within the context of an activity in present time and allowed for the triggering of meaningful emotional experiences, thus promoting well-being. However, as Ulman (1975b) has pointed out, the effectiveness of any creative session depends on the quality of life during those other 23 or so hours of the person's day.

In order to explore creativity's role in promoting well-being, Spaniol (2001) took a phenomenological approach and interviewed nine artists with mental illness. Three major themes emerged from her work which point to the functional nature of art in the lives of these artists. These are:

- The social function of art; in which connections were made with others, thus minimising the profound sense of isolation that often accompanies

mental illness. Connections in childhood in the form of a caregiver and connections in adulthood in the form of a mentor are, according to Spaniol (2001), essential to creative development. Art also provides the person with a social role as artist, in which they are distinguished for their strengths as opposed to their disability.

- The psychological function of art; in which the person strives for self-understanding, self-expression and self-healing.

- The formal function of art; in which form, by providing structure to the art, enables the artist to convey meaning, thus bridging the gap between artist and viewer.

Spaniol (2001) argues that these artists used their creativity to strive towards emotional wellness; suggesting that creativity is more closely associated with mental wellness than mental illness. This contradicts the notion that people with mental illness are irrational and out of control and it challenges professionals to look for areas of strength in people rather than focus on disability and to work toward what people with dementia can accomplish in spite of cognitive decline (Greene Stewart, 2002).

Creativity as communication of self

Creating images has been a basic mode of communication since primeval times (Naumberg, 1975). Allan and Killick (2000) suggest that both the artistic process and the product may be forms of self-expression for those with dementia. It could be a private act of communication with the self or it could be a form of communication between individuals in which an outlet is provided for thoughts, feelings or insights. For the person with dementia, exclusion from normal

conversation and interaction often occurs as a result of prevailing assumptions and expectations that people hold surrounding cognitive and communicative decline. Exclusion takes the form of ignoring what people have to say and ultimately failing to engage with them on an equal level (see Kitwood's [1997] malignant social psychology and Sabat's [2006] malignant positioning). What is clear is that alternative means of self-expression must be provided for people with dementia as other communication abilities decline.

In response to the recognition that people with dementia have much to say if alternative means of communication can be provided, there has been an upsurge of interest in providing opportunities for creativity, whether it be through painting, collage, music, textile work, drama or photography. Craig (2001:3) noted "it was as though through the arts they had found another way to communicate, to express self". Similarly, Harlan (1993) suggests that the art-making process produces emotional healing through verbal and non-verbal communication. However, both fail to demonstrate how they arrive at their conclusions. Wood (1998b:33) suggests that the influence of artwork can extend beyond the person who created it; out to others in the person's social world, or even beyond. This can have the effect of altering others' perceptions of the person, maybe because "the image maintains and conveys something of the continuing humanity of the person".

Creativity in person-centred care

According to Rogers (1954), nourishing creativity in others requires that a facilitator, teacher or carer accepts the individual as being of unconditional worth; he/she has unconditional faith in the potential of the person with

dementia. The facilitator must provide a climate in which external evaluation is absent, where the facilitator does not form judgements from his/her own locus of evaluation. The facilitator must engage in empathic understanding in which he/she truly sees the person and what the person is feeling, in which he/she enters the person's private world and sees it as it appears to him/her. Finally, the facilitator must allow psychological freedom for symbolic expression. By these means, a safe environment is created for creative expression to emerge.

However, while this ideology is commendable, practitioners have raised concerns about its applicability (Packer, 2000b) and the struggle by practitioners to implement its philosophy effectively (Sheard, 2004). For, as most adults have themselves not experienced complete genuineness in other people, have not been listened to empathically and have not been loved unconditionally (Silverstone, 1997), how then can they truly work in these ways for others? This is the challenge for those providing, not only person-centred creative sessions, but person-centred dementia care as a whole, and it is this point which, after much thought, has become the focus of my study.

My approach to creativity in this study

Having studied the literature, my position, as someone outwith the art therapy field, but with a creative background and a symbolic interactionist/social constructionist focus, is to see creativity in dementia care as a communicative act, often achieved in interaction with others. I do not wish to analyse it for unresolved conflict or deep psychological symbolism. Instead, I see the work as an expression from the person, with or without conscious, intrinsic meaning. Its

value lies in its creation, its product and, ultimately in its potential for promoting positive interaction and fostering well-being.

Much of the literature, while encouraging and sometimes inspiring, is lacking in empirical evidence to support its claims for success and much of it focuses on people with dementia living at home or in residential care. The paucity of empirical studies exploring creative sessions with those with dementia in long-term care is glaring, and it is for these reasons that I undertook this study. However, as discussed in chapter 1, my focus has changed; from seeking a relationship between creativity, well-being and Self-expression, to one which recognises the transactional role of interactions, and which seeks to explore creativity as a possible catalyst in facilitating person-centred interactions which will foster well-being and Self-expression of people with dementia in long-term care.

Conclusion

In this chapter, I have introduced Kitwood (1997) and Sabat (2001) as key works in this thesis. I have suggested that, while Sabat positions himself as a constructionist, his work also resonates with symbolic interactionism in that he stresses the role of interactions, in particular positioning, in undermining selfhood. Kitwood's (1997) work, drawing on the discourses of ethics and social psychology, also has parallels with interactionist and constructionist thinking in that he stresses the circularity of interaction in undermining or upholding personhood, while also recognising the influence of deeply embedded cultural assumptions in driving the interactions of carers.

I have discussed Kitwood's (1997) work on personhood and person-centred care and Sabat's (2001) Selfs 1-3 framework. I have discussed Kitwood's (1997) elements of malignant social psychology and positive person work as being influential in undermining or upholding personhood and damaging or nurturing well-being. I have described Sabat's three aspects of selfhood: Selfs 1-3 and have discussed philosophical and social influences on ideas of loss or maintenance of self. I have proposed that the idea of "loss of self" is influenced by the legacy of Cartesian philosophy and with deeply embedded, socially constructed cultural assumptions. I have briefly pointed to social practices such as positioning, attribution and distancing, along with widespread ageism, as contributing to perceptions of loss of self. This is Kitwood's (1997) old culture of dementia care.

The alternative approach; drawing on the writings and experiences of people with dementia themselves, and on sociological and psychological research, argues that self of people with dementia is not lost with cognitive decline. It argues that, with or without dementia, our sense of self shifts and changes over time; we build and present ourselves through social interaction and co-construction with others. This approach, which reflects and reinforces the changing conceptualisations of self, recognises an enduring core self and focuses on the identity work; through verbal and visual communication, that people with dementia carry out in interactions and relationships. It also proposes a fundamental shift in thinking; from seeing neuropathology as causing disintegration of self to focusing on the role that others play in nurturing or damaging self of people with dementia. It places particular emphasis on

trying to eradicate malignant social psychology and promote positive person work in order to uphold personhood and nurture selfhood. This is the new culture of dementia care.

In recognition of the difficulties in carrying out person-centred care, I have raised creativity as an alternative means of facilitating person-centred interactions. I have highlighted the differing positions between the American and British art therapy fields and have pointed to empirical and analytical gaps in much of the literature. For example, while many of the authors cited above talk discursively of benefits, improvements, potentials and therapeutic outcomes of various kinds, they provide little in the way of analyses to support the inferences made about the "success" of the creative input under investigation. Some writers have talked of expression or consolidation of self, however, none have given working definitions or conceptualisations of "self" and none have linked different manifestations of self to the different types of interaction encountered by people with dementia in their daily lives. Others talk of improvements in well-being, without measuring what these improvements are, or how they too depend on different types of interactions.

This research intends to address some of these gaps; by exploring interactions within the creative process in relation to well-being and Self-expression of people with dementia, and by raising creativity's potential as a means of facilitating care which upholds personhood and nurtures Self.

In the following chapter, I will set out my methodological position, discuss and justify the methods I chose, describe some of the practicalities and ethics of data-collection and discuss data-analysis and management.

Chapter 4: Methodology and methods

Introduction

In this chapter, I will discuss ethnography as my methodological approach and explain how its use allows me to gain a deeper understanding of participants' social worlds. I will then discuss the research design, and the choice of and entry into the research setting. I will discuss the chosen methods for data-collection, which fit well with the interpretivist stances of symbolic interactionism and social constructionism. These are Dementia Care Mapping (DCM), video-recording creative sessions, focused conversations with participants along with keeping extensive fieldnotes. Finally, I will discuss how I constructed data sets for analysis, how I carried out data-analysis and how I managed the data.

An ethnographic methodology

Silverman (2005) describes methodology as a general approach to studying a research topic. It includes the choices we make about cases to study, methods of data-collection and types of data-analysis; all the while documenting the rationale behind the research design and analysis. As interpretivist epistemologies attempt to understand the complexities and meanings of interactions within social situations, an ethnographic methodology is well suited for this quest.

The term ethnography derives from "ethno" which means "folk", and "graph" which derives from "writing". Ethnography, then, is social scientific writing of

folks (Silverman, 2005). Ethnography is characterised by an attempt to achieve some level of understanding from the perspective of those being studied which, after detailed analysis, can then be shared with others (Wolcott, 1995). Such understanding requires immersion into the group being studied. As Goffman (1961:7) states:

…any group of persons – prisoners, primitives, pilots or patients – develop a life of their own that becomes meaningful, reasonable and normal once you get close to it, and… a good way to learn about any of these worlds is to submit oneself in the company of the members to the daily round of petty contingencies to which they are subject.

My study, while seeking an understanding of the social worlds of a group of people with dementia, also had a specific focus; in that it sought to answer specific questions. In this sense, it was a focused ethnography (Roper and Shapira, 2000); needing a shorter time-span than more open ethnographies. This suited the time-span available to me as a full-time Ph.D. student aiming to complete in three years.

During ethnographic fieldwork, the researcher immerses him/herself personally in the lives and activities of a particular group or individuals (Wolcott, 1995). This involves using different strategies to bring ways of understanding into awareness and to make them explicit and public (Agar, 1996). Such strategies may include non-participant observation, which is central to ethnography (Roper and Shapira, 2000), formal and informal interviews, examination of documents and texts and copious note-taking. In my study, I used non-participant

observation, informal and focused conversations, Dementia Care Mapping, video-recording and fieldnotes as methods for data-collection.

Negotiating access

Ethnography most often requires negotiation with gatekeepers. These are key personnel who hold the power to grant or withhold access to the setting (Hammersley and Atkinson, 1983). One way of overcoming the difficulties of gaining access is to take on a covert role; not disclosing that one is a researcher. This approach is contentious and is fraught with ethical issues; it involves deception and it violates the principle of informed consent (Bulmer, 2001), and for these reasons, it is difficult to justify. More often, the researcher opts for an overt role (which I did) and uses a range of strategies to gain entry to the setting, such as using informal contacts, seeking support from an influential person in the setting, arranging introductory meetings in order to address concerns or offering something in return for allowing access (e.g. a feedback session).

In order to answer my research questions (see pages15 and 16), I needed to find a setting in which creativity was encouraged. As I hope to work in the NHS on receipt of the doctorate and as there is no research on the experiences of people with dementia in long-term NHS settings in relation to creativity, well-being and Self-expression, I decided to confine my search to settings within the NHS. Having contacted several long-term NHS settings, to discover that they provided minimal or no creative input, I found a large hospital with several psycho-geriatric wards in which a team of occupational therapists (OT) worked and in which the management and consultants were willing for me to carry out

the research. Three of the wards fulfilled my initial criteria: they provided long-term care for people with dementia and there was regular provision of creative input, albeit not by ward staff but by OT staff. Thus, wards 1, 2 and 3 within Moorhills Hospital (pseudonym) became the fieldwork settings.

Over a period of eight months, I held meetings with gatekeepers; the hospital manager, consultants, charge nurses and OT staff in which we discussed the details of how I intended to go about data-collection, potential problems I might encounter and concerns from OT staff regarding participant anonymity and safety. I remained open and honest throughout this time in an attempt to be as transparent in my aims as possible and I received constant support and willing consent from them to carry out the research. I will discuss, in detail, the process of gaining consent from all participants in the following chapter.

Ethnographic understanding and writing

Ethnography can be an attempt to understand ourselves through understanding others (Wolcott, 1995) and perhaps this is its ultimate aim. This is eloquently stated by Geertz (1973:54):

> *The anthropologist broods…upon the true and insignificant, glimpsing in it, or so he thinks, fleetingly and insecurely, the disturbing, changeful image of himself.*

I too have changed throughout this study; becoming reflexive, self-critical and more humane, and this has had a deep and lasting impact on how I care for people with dementia and how I engage with others in my life.

Contrary to early anthropological texts, fieldwork is no longer the hidden face of ethnography (Baszanger and Dodier, 1997), but emerges in the written work. Ethnography, then, is also the act of writing from fieldnotes and the development of a completed text. Wolcott (1995:210) describes the art involved in ethnographic writing:

> *The art is to present material in an engaging yet coherent manner sufficient to hold the interest of a reader who may not expect to be entertained but hopes not to be bored.*

I have aimed for this outcome in the writing of my thesis.

Ethnography in exploring the lives of people with dementia

Ethnography is increasingly being used to explore the social worlds of people with dementia, particularly in institutional settings. For example, Vittoria (1998) explored how staff in one long-term unit engaged in communicative care in order to preserve residents' identity. Chatterji (1998) explored the anguish of a man admitted to a care home, although his wife and formal carers mainly told his story. Lee-Treweek (2000) explored the culture of a nursing home from the perspectives of untrained care staff and Archibald (2002) explored how staff constructed sexuality in a care home and how this influenced their interactions with residents. Similarly, Ward et al. (2005) revealed that care staff often see patients' sexual expression as problematic. Kontos (2004) explored how formal and informal discourse shaped the selfhood of a man with dementia. However, these studies, while attempting to understand the social worlds of people with dementia did not give them a central voice; instead allowing informal and formal carers a proxy voice. In order to follow Kitwood's (1997) maxim that the person

with dementia should come first, researchers are now attempting to include interviews with people with dementia as part of their research as discussed later. In my research, along with focused conversations with three participants, I attempted to give all participants a central "voice" by attending to and seeking meaning in their verbal and visual expressions of well/ill-being and Self, as I will discuss in chapters 6 and 7.

Gaining ethical approval

Having contacted the hospital management, consultants and OT staff and having received their support, I needed to obtain formal ethical approval to carry out the study. Because I proposed to work with vulnerable adults (HMSO, 2000), I was required to seek ethical approval from the Multi-Centre Research Ethics Committee (MREC), Scotland. The initial application to MREC was not approved, one of the reasons being:

> *There was doubt that the most severely demented patients were the most likely to benefit* (from creative sessions)*, and therefore doubt that they were the right participants.*

Wilkinson (2002) experienced similar doubts from other researchers, members of ethics committees and practitioners about the feasibility or possibility of engaging people with dementia in research; suggesting that negative positioning occurs even within professional groups.

My second application to MREC was more explicit about differing potential and abilities, regardless of perceived severity of dementia. This time the application was approved. I also received ethical approval from the University of Stirling's

Nursing & Midwifery departmental ethics committee, the Local Research Ethics Committee (LREC) and from Moorhills Hospital's Research and Development (R&D) Department.

Formal ethical approval serves as a prompt to a rigorous ethical approach to research; stressing the need for informed consent and participant anonymity and confidentiality, ensuring psychological and physical safety of participants and researcher, ensuring that data is stored securely and ensuring that analysis of data is rigorous and impartial. I will discuss such ethical issues throughout the thesis; to reflect the idea that ethics in research is ongoing and requires constant reflection on practice, motives and decisions throughout and beyond the research process.

In the following chapter, I discuss the process of gaining consent from all parties, with particular emphasis on how I sought ongoing consent from the 14 participants with dementia for each stage of the study.

Research design

From June to December 2005, I collected data from each of the three wards in turn. Table 1, below, summarises the three stages of data collection, their purposes, time scales, methods used and data sources for analysis.

Table 1. Stages of data collection

Stages	Purpose	Time scale	Methods	Data source
1	To become familiar with participants and visa versa. To observe and document their social worlds.	2 weeks in each ward.	Non-participant observation.	Fieldnotes.
2	To document interaction types experienced by participants in wards and creative sessions, and their responses to interactions in terms of well/ill-being and Self-expression. Continued observation and documentation.	6-7 weeks in each ward.	6-hour DCMs on creative session days and video-recording creative sessions. Non-participant observation.	DCM data. Fieldnotes and DCM data derived from video recordings. Fieldnotes.
3	To seek participants' opinions on creative sessions.	1 hour for each participant.	Focused conversations with participants.	Transcripts. Fieldnotes.

Of the 14 participants who took part in the study, six did not take part in creative sessions. This was due to:

- their own continued refusal to take part,

- the inability of OT staff to include everyone in the sessions necessitating decisions to be made as to whom to include or exclude,

- participants' deteriorating ability,

- the arrival of one participant's wife every afternoon.

I used data from these six participants to explore how they fared in terms of well/ill-being and Self-expression in everyday ward life, in the absence of extra input from OT staff.

Methods of data-collection

In this section, I will describe the ethnographic experience and the structured methods of data-collection that I chose: DCM, video-recording and focused conversations. I will discuss their strengths and limitations, their uses in research with people with dementia and describe my own experiences of using these methods. Table 2, below, gives an overview of how many times each participant engaged in each stage of data-collection.

Table 2. Methods of data-collection and frequency of participation*.

Participants	Number of 6-hour DCMs	Number of creative sessions attended	Number of video recordings	Number of focused conversations
Ward 1				
Edward	5	2	2	0
Florence	2	1 (unsuccessful)	1 (unsuccessful)	0
Nora	4	0	0	0
Ward 2				
Mary	6	4	4	0
Hannah	6	5	4	0
Isabel	6	4	4	1
Brenda	6	0	0	0
Kate	6	0	0	0
Ward 3				
Bill	4	4	4	1
William	4	3	3	1
John	6	5 (1 very brief)	5 (1 very brief)	0
Charlie	4	0	0	0
Paul	2	0	0	0

* See Appendix 1 for a brief introduction to participants.

The ethnographic experience

Throughout the study, I tried to experience participants' social worlds in the wards and creative sessions. This entailed intense non-participant observation. I spent six to eight hours every day, sitting or walking with participants and either chatting with them or just being with them. I concentrated on exploring the wards with my senses; experiencing smells, sounds and sights. When I could, I

would jot down notes, using key words and phrases, in a notebook tied around my waist. On creative session days (stage 2), I took a more structured approach and carried out a 6-hour Dementia Care Map, interrupted only to video record the creative session.

During stage 1, in which I spent two weeks immersed in participants' social worlds, I often became overwhelmed by the experience; whether it was the dismal or oppressive ward environment, the restlessness or distress of participants or the hostility of ward staff. I would then leave the ward, take lungfuls of fresh air and write up my jottings in detail. I would return, ready to resume my immersion in the lives of the participants. Here, though, is what I wrote after a particularly fraught evening in ward 1:

> *I'm feeling the tension too. My chest tightens and I try to take deep breaths. I need to get out soon. Most of the participants are tense and restless, the air is thick with tension but the staff seem oblivious… The relief as I close the door behind me is palpable.*

Trying to understand participants' social worlds involved being alert to all that was going on around me, while trying not to draw excessive attention to myself. Here, from my fieldnotes is how I observed staff interactions in ward 1:

> *I try not to look at them* (the staff) *too much. Instead, I focus on chatting with participants while keeping an ear open for what's going on.*

One day, in ward 1, a student nurse found a jigsaw and she and some of the women sat and worked on it. After a while, I joined them and recorded in my fieldnotes:

> *This gives me a chance to be occupied and observe.*

In ward 2, I spent my time walking with Brenda, sitting with Kate while she held my hand or talking with Hannah, Mary or Isabel. I also spent time with the other women in the ward, who sought me out or who seemed distressed or isolated. Here, from my fieldnotes is how I tried to engage with Brenda, who spent many hours walking alone, and how just being with her seemed sufficient:

> *Brenda is walking alone and I join her and walk with her for a bit. We walk up and down the ward together and she holds my hand tightly. Then she sits on the couch at the end of the corridor and I sit with her. She takes my hand and strokes my arm and we sit like this for over 10 minutes. Then she stands up and starts to walk again, taking me with her…*

In ward 3, followed by a small group of men who were not participants, I walked with Charlie and tried to comfort him, I chatted with Bill and William, accompanied John as he tried to occupy himself, tried to engage with Kevin and sat with Paul who smiled at me and held my hand. While I also engaged with non-participants, I did not write notes about them unless it was to document specific staff interactions.

All the time, I soaked up participants' shifting moods and experiences, periodically jotting down notes and later, writing them up in detail. As I will discuss in chapter 5, this was not always a comfortable or an easy task.

Dementia Care Mapping

In stage 2, along with keeping ongoing fieldnotes from non-participant observation, I carried out a 6-hour Dementia Care Map (DCM) on creative session days. Before justifying my choice of DCM and discussing my own experiences of mapping, I will first describe the origins of DCM, its use in research and its strengths and limitations.

In the late 1980s, a concern with the delivery of care and hence the quality of life of people with dementia led to the development of DCM by Tom Kitwood and Kathleen Bredin. Its aim was to bring about improvements in care for people with dementia, to highlight good and poor practice from their perspectives and to empower staff to work within the principles of person-centeredness (Bradford Dementia Group, 1997). DCM claims to be a powerful observational tool, which evaluates the quality of care people with dementia receive in formal care settings such as hospitals, day centres and residential and nursing homes. It is an attempt to observe and understand the social worlds of people with dementia from their standpoints as opposed to the standpoints and frames of reference of those without dementia. Its grounding philosophy is person-centeredness and its aim is to measure how person-centred philosophy is applied in care environments and experienced by those with dementia (Kuhn et al., 2000). Ultimately, DCM was developed as a tool for consciousness-raising in caregivers (Neel, 2002); to promote change in the

negative care environments that many people with dementia still experience and to foster an environment in which personhood is respected and maintained.

DCM involves making a series of detailed observations over at least six hours of up to eight people with dementia in the public spaces within a care setting. The "mapper" records data every five minutes onto a specially designed form and chooses from 24 possible behaviour category codes (BCC); that which best represents the behaviour and activity of each person with dementia. Alongside documenting BCCs, the mapper evaluates the relative well or ill-being (WIB) value of each person, with levels ranging from +5, +3, +1 for well-being through to -1, -3 and -5 to reflect increasing levels of ill-being (see Appendix 2 for BCCs and WIB values). The mapper also documents instances in which the personhood of the person is undermined by care staff, following Kitwood's 17 elements of malignant social psychology, and instances in which personhood is upheld through his ten elements of positive person work.

The mapper must attempt to code what people with dementia are experiencing rather than what the mapper assumes they might be experiencing or what she thinks the caregiver intends them to experience. This requires attending a three-day training course in order to develop a sound knowledge of DCM and its operational rules (see Appendix 3 for operational rules).

While carrying out DCM, there are several ethical points to consider (Bradford Dementia Group, 1997):

- The mapper must work within person-centred principles, in relation to people with dementia and caregivers.

- She must work within the ethical guidelines and codes of practice which are established within the care setting.

- She must try to introduce herself to all caregivers and all those she intends to map and explain why she is there and what she plans to do.

- She must strive to make mapping as unobtrusive as possible without being covert.

- She must stop mapping if a person with dementia becomes disturbed by her presence.

- She must give clear and honest explanations to caregivers, be prepared to answer questions and to show them her documentation.

- She must avoid being judgemental as this will be counter-productive in feedback sessions.

- During mapping, if she sees that someone is in danger of hurting him/herself she must intervene to protect him/her.

- If the mapper witnesses abuse of a person with dementia, she must notify the manager of the setting.

DCM in research

While originally designed as an audit tool for improving the quality of care in care settings, DCM is increasingly being used in research which also seeks to improve quality of care (Brooker, 2003). In 1995, Bredin and Kitwood published the first substantial piece of research using DCM, which evaluated the effects of

a ward merger on the lives of people with dementia. Williams and Rees (1997) used DCM to evaluate the adoption of person-centred principles in a care setting for "elderly mentally ill". Brooker et al. (1998) explored its use as an audit tool over three years within a British Mental Health Trust and found it to be increasingly useful in improving quality of care. Brooker and Duce (2000) used the WIB (well or ill-being) values in DCM to compare the effects of different types of activity on the well-being of people with dementia in three day hospitals. Innes and Surr (2001) evaluated the extent to which psycho-social needs of people with dementia were met in six nursing homes in England. Edelman et al. (2004) explored the association between highest levels of cognitive impairment and WIB values and concluded that those who were most cognitively impaired were most at risk of experiencing low quality of life as measured by low WIB values.

Research has also explored the validity of DCM (Fossey et al., 2002) and found it to have good internal consistency (good agreement between the different DCM indices). They also found that WIB values correlated well with an informant rated quality of life scale, suggesting that WIB values are good indicators of the quality of life experienced by people with dementia. Woods and Lintern (2003), however, caution against generalising the results of one DCM to other settings.

Strengths of DCM

Barnett (2000:65) talks of her experiences of mapping, where she chose a low chair, or sat on the floor and learned "just to settle into being in that environment, just as my fellows in that environment were just 'being'". It is only

by truly being with people in their environment that one can gain insight into their social worlds. DCM has the power to do just that; by capturing the processes and the outcomes of care, from the positions of people with dementia. The application of DCM within a care setting can achieve its goal of increasing the well-being of people with dementia (Brooker et al., 1998; Kuhn et al., 2000). This is achieved through highlighting, in a non-judgemental manner, ways in which care can be improved and then collaborating with caregivers in developing manageable goals for achieving such improvements. Follow-up mapping sessions can then chart progress and provide further feedback and reinforcement for caregivers. This, the consciousness-raising (Neel, 2002) aspect of DCM, has the power to influence positive change in the perceptions of caregivers and to foster person-centred care. DCM, by identifying aspects of good care, can boost staff morale and encourage caregivers to recognise the importance and potential rewards of their work (Williams and Rees, 1997). I attempted to follow the consciousness-raising principles of DCM, by holding feedback sessions with ward staff on completion of my time in each ward. This had varied degrees of success, as I will describe later.

Limitations of DCM

Capstick (2003) agues that DCM over-emphasises the influence that direct care staff have on the overall quality of care that people with dementia receive. There are other factors: the physical environment over which care staff often have little control, availability of resources, adequate training, management support and government funding which will influence the care environment, the care that people with dementia receive and on their quality of life.

For an approach that puts person-centredness at its core, DCM does not provide space for hearing the voice of the person with dementia (Capstick, 2003). This does seem to be a critical omission in the design of this tool, which I attempted to address by taking an ethnographic approach, which included non-participant observation, video-recording creative sessions and carrying out focused conversations with participants.

Thornton et al. (2004) found unacceptably low levels of inter-observer agreement among routine care staff, who were trained in DCM. This could be explained by the complexity of the tool, ineffective training and inexperience with the tool or an attempt by mappers to map too many people at once. Similarly, Edelman et al. (2004) have criticised DCM for its complexity, particularly in its coding and they suggest that fewer codes could be used. However, this would then reduce the possibilities for documenting the subtleties of behaviour. Brooker (2002) acknowledges that DCM is a complex tool and argues that it requires skill and care in its teaching and its use. With a sound knowledge of operational rules and increasing experience, the mapper should become more proficient in deciding and documenting BCCs and WIB values (Surr and Bonde Neilson, 2003). I found this to be the case, as with practice, I was quickly able to mentally scan between operational rules and apply the appropriate BCC and WIB value.

Thornton et al. (2004) also criticise DCM's emphasis on prioritising BCCs that reflect activity rather than passivity on the part of the person being mapped. This rule could potentially underestimate and under-report the amount of time

spent in inactivity and give an inaccurate picture of the experiences of the person with dementia. However, as DCM is aimed at improving the quality of caregivers' care, in a person-centred way, there is a balance to be struck between delivering negative feedback, which further demoralises caregivers and less negative feedback, which points to some levels of good practice in a way that encourages caregivers to see their work in a positive light.

Brooker et al. (1998) identified varying levels of staff anxiety throughout their mapping sessions. This is elaborated on by Neel (2002) who encountered anger, defensiveness and confrontation from caregivers when he gave negative feedback to them. This highlights the need for imparting sufficient and honest information, providing reassurance, remaining non-judgemental, interacting with caregivers in a person-centred way and feeding back to them promptly and in an encouraging manner. Mackenzie et al. (2002), in addressing these needs, provide detailed guidelines for delivering feedback sessions to caregivers.

My justifications for using DCM

Despite these limitations, no one has yet come up with a better method for evaluating dementia care (Innes et al., 2000). In using this method, I reflect my person-centred stance and I expand on the body of work that seeks to evaluate the care of people with dementia in formal care settings. As it has been shown to be a valid tool (Fossey et al., 2002) and as it remains the method of choice for those concerned with improving the lives of people with dementia, it is also one of the tools of choice in this research. Finally, its operational rules demand a consistent approach to data-collection, which can avoid the potential bias of using fieldnotes alone.

Practical issues while mapping

Carrying out a 6-hour map was a draining experience, particularly as social and environmental conditions in the wards were poor. I had to make careful preparations in order to carry out the full six hours of mapping with consistency and concentration. I made sure I had sufficient coding sheets, a watch, pencils, a pencil sharpener, an eraser, notepaper and the DCM manual. I brought snacks and water, as taking a break was not advisable. I wore layers that could be taken off and put on and wore comfortable shoes as I anticipated a lot of walking.

Mapping participants

I carried out a 6-hour DCM on every creative session day. Altogether, I carried out 17x 6-hour DCMs over six months of fieldwork. See Table 2 (page 83) for how many times each participant was mapped.

In ward 1, both Nora and Edward usually sat in armchairs in the corridor and Florence usually sat where the corridor widened into a sitting room area or alone at the end of the corridor. Armed with a bag containing what I needed, I chose a low stool to sit on in order to remain as inconspicuous as possible while also being able to see participants. I observed them closely and, following operational rules, I documented the appropriate behaviour category code and well or ill-being value for each participant every five minutes for six hours. If participants moved out of realistic mapping distance, I would follow them and observe from a discrete distance. If I had to intervene to protect or comfort participants, I marked the relevant timeframe with a slash. I intervened only occasionally in ward 1, in contrast to the many times I intervened in wards 2 and

3, as described and justified in the next chapter. Here, from my fieldnotes is an account of the start of a map in ward 1:

> *Edward sits in the corridor and Nora is just two armchairs down from him. I find a low footstool and sit at a distance where I can see them both, while also keeping out of the way of staff and other patients. I have with me a big bag of chocolate raisins and a bottle of water. These will see me through the next six hours.*

In ward 2, as it was fairly easy to keep track of everyone, I mapped all five women at once. Brenda spent most of her days walking up and down the corridor or round the sitting room. There were times during each map when she walked out of sight and on these occasions I put V (for vacant) in the appropriate timeframe. Kate most often sat in a disengaged manner or slept until evening, when she would become more alert and walk around trying to make contact with people. Hannah, Mary and Isabel were generally sedentary and sat in the sitting room. As in ward 1, I interrupted mapping if I saw someone becoming distressed or in potential danger.

In ward 3, I quickly realised that I would be unable to map all six men at once. Three factors led me to decide to map the men in small groups.

- In stage 1, several other men became attached to me and walked or sat with me throughout the day. By stage 2, these men were familiar with me and reached out to me and I was reluctant to deny them the opportunity of contact with me while I was mapping.

- The ward layout and the mobility of some of the men meant that I would be unable to accurately keep track of all six within each five-minute timeframe.

- It became clear that I would be unable to map Kevin for more than a few hours as his wife came to visit every day. Because she visited on creative session days, he never took part. While I did not map Kevin, I continued to make notes of his days.

Ward 3 was the most challenging of the three wards to map: partly because the men were more mobile; partly because I had a following of other men who wanted to be with me and partly because I was uncomfortable with the harshness of some of the staff towards the men and aware of their hostility towards me. I will return to this in chapters 6 and 7.

When the art therapist or OT staff came to set the tables with paints and paper for the creative session, I would follow whichever participant agreed to join them and, with their consent as described in the following chapter, would set up the video camera to record the session. During this time, other participants were not mapped until I rejoined them after the creative session. I then continued to map all participants for the remainder of the six hours.

Debriefing

After every map, I always went to each participant in turn and chatted or walked with them and thanked them for allowing me to write about their days. This was as much to resolve my own guilt at not being able to engage with them as I

would have liked, as it was to debrief with them. Here, for example, from ward 1 is one occasion:

As soon as I have finished mapping, I go to Nora and sit with her. I say: 'you've not been so good today, Nora' and she responds that she has not been so well. 'I wish I was home' she says sadly. I sit with her and keep her company and soon her mood lightens.

Difficulties and dilemmas when mapping

Although I felt I had prepared well for mapping: having practiced at my workplace and spoken to my supervisors and DCM trainers about practical and ethical issues, I regularly encountered difficulties and dilemmas with which I grappled and which I describe below.

Adhering to operational rules

DCM was developed with western concepts of well-being in mind; with an emphasis on activity, assertiveness, self-expression and the ability to initiate social contact. Following this way of thinking, BCCs are ordered in a hierarchy; with activity taking precedence over inactivity. This means that, if a participant was in distress or disengaged and someone spoke fleetingly to him/her, I had to code this as a positive interaction (usually A+1), even if, within the same timeframe s/he became distressed or disengaged again. I often felt that the final picture told an overly optimistic story of the amount of interaction participants received. My solution was to take detailed fieldnotes along with carrying out DCM in order to try to capture, as accurately as possible, how participants fared.

While positive values are ascribed to activity, negative values are ascribed to certain inactivities such as C (cool: being socially uninvolved, withdrawn). Capstick (2003) argues that DCM's interpretation of C is overly prescriptive and pessimistic and does not allow for the possibility that the person may be in a meditative state, such as that espoused in the theory of gerotranscendence (Tornstam, 1997), which I discussed in chapter 1. Further, if a person has always been reserved, introverted and content with her own company, it is less likely that she will initiate social contact than someone who has been sociable and outgoing. However, operational rules dictate that C is given only negative values, implying that this is an undesirable state to be in. There were times when I felt that I inferred a state of ill-being onto a participant erroneously, which appears to contradict the person-centred ethos of DCM. I struggled with this code, particularly when mapping Kate in ward 2, as she often sat, stretched out, looking into space, seemingly disengaged, but not in an obvious state of ill-being. However, as I intended to adhere to the coding descriptors and operational rules (see Appendices 2 and 3), I had to code this as C-1.

Selfhood and DCM

For an approach that puts person-centredness at its core, DCM does not provide space for recognising Self-expression of the person with dementia; as discussed later. These limitations in DCM's approach reflect the thinking when it was first developed; that the capacity for Self-expression is limited in people with dementia. As such, further development of DCM is required in order to do justice to the capacity for Self-expression. This is unlikely to occur until DCM 9 or until a "family of DCM measures" is developed (Brooker, 2003).

In an attempt to resolve this limitation, I took a toolkit approach to data-collection (Innes and Kelly, 2007); using non-participant observation, informal and focused conversations, video-recordings and keeping extensive fieldnotes along with DCM. In so doing, I have tried to open the opportunity for those with dementia who took part in my research to express Self in their own unique ways.

Lone mapping

Because I was mapping alone, I had several issues to consider. Participants were potentially scattered about the ward, and engaged in different types of activity, for example someone might have been engaged in conversation in one area while someone else was sleeping in another area. Sometimes, I was unable to map each person for the full five minutes and had to decide whether to capture the essence of what each person was doing over a shorter time or to omit one person's BCC for that timeframe. On each occasion, I made a decision based on whether I felt I had sufficient information, or not, on how participants fared during that timeframe. If I felt that my information was too scanty, I omitted the data from the timeframe and wrote explanatory notes as to why the timeframe was empty.

As a lone mapper, I had to consider the reliability of my coding: the degree to which my choice of coding adhered to the DCM manual and its operational rules. Surr and Bonde Neilson (2003) recommend that mappers work with at least one other mapper during any DCM evaluation. This allows them to check for inter-rater reliability: the extent to which two mappers' maps will be consistent with each other (Woods and Lintern, 2003). As a lone mapper, I

could not check my reliability and was vulnerable to a critique of my coding, so I took other measures to ensure reliability. I took detailed notes to accompany BCCs and WIB values in order to later justify coding decisions, I sought advice from one of my supervisors who is a DCM trainer when I had queries about particular codings and I changed codings in hindsight if they later seemed inappropriate.

A further issue that I had to consider, in the absence of a fellow mapper, was how to debrief, particularly when struggling to cope with mapping poor social and physical environments. Mapping was a painful experience, especially as, over a period of time, I had developed an empathy with my participants. The need to follow DCM rules and remove myself from their world was very difficult and resulted in feelings of guilt at not being able to engage with them while mapping. I partially resolved my guilt by engaging with participants on completion of the map, as described above. This helped to re-establish a rapport with them, and acted as debriefing sessions in which I discussed aspects of their day with them. In order to resolve some of these issues, Edwards (2005) calls for a national support network for mappers, however, as my difficulties were heavily laden with emotion and I did not know other mappers well enough to discuss emotional difficulties, I resorted to seeking support from fellow Ph.D. students, supervisors and friends.

Staff feedback sessions

Part of the consciousness-changing and quality improvement ethos of DCM requires that the mapper gives feedback to ward staff. On completion of my time on each ward, I arranged to return and meet with the staff.

When I returned to each ward, I gave the staff a summary sheet of the principles of person-centred care and points pertaining to each ward (Appendix 4), and a selection of participants' Individual Care Summaries and Positive Event Records (see Appendices 5 and 6 for an example of each). In wards 1 and 2, the staff were receptive and joined in with their thoughts and anecdotes to further highlight points I had raised. I felt that these sessions had been successful in sensitively raising staff awareness to the impact of their actions (or inaction) on participants and non-participants.

In ward 3, I was acutely aware of the resistance of some of the care assistants who attended the meeting:

> *X and Y's body language (and X's snigger) suggested resistance and scepticism.*

I felt that the presence of two dominant care assistants discouraged any constructive discussion, despite my encouragement. I left the meeting feeling I had failed the men of ward 3.

Video-recording

On creative session days, I interrupted mapping to video-record those participants who agreed to join the OT staff in painting or doing collage work at the creative session. Before justifying and describing my own use of video, I will discuss video in ethnography, its use in research with people with dementia and ethical issues to consider when video-recording vulnerable people.

Pink (2001) suggests that video representations of any length or style which are used to represent ethnographic knowledge may be referred to as ethnographic video. The focus of such video representations is usually some form of social interaction, in which visual and verbal cues are recorded (Rosenstein, 2002).

The documentary tradition of photography and film within ethnography emerged in the late 19th century in Europe and America as an attempt to capture the "actualities" of the world (Ball and Smith, 2001:303). However, within sociology, photography and film have occupied a much smaller place. The use of these visual methods have most often been ascribed a supporting role in sociology, being seen more as an aid to the communication and presentation of the written word than as a method in its own right (Harrison, 1996).

This view is now changing. The increasing availability of sophisticated video-recording equipment now offers wider opportunities for examining the subtleties of social interaction, particularly visual aspects of communication such as body movement, inclination, gaze and people's ownership of spatial relations. For example, Watson (1997) video-recorded the naturally occurring behaviour of people waiting at a bus stop to explore social organization while Heath (2004) used video-technology to explore the ways in which patients and doctors accomplished talk during medical consultations. The use of video not only allows for detailed coding, interpretation and repeated checking, but can be subsequently analysed by independent researchers if necessary.

Rosenstein (2002), in a review of the literature, identified three areas in which video is used in research: as a tool for observation, as a mechanism for giving feedback and as a means of distance learning and consulting via video conferencing. In my research, I used video for the first two of these purposes. First, I used it as an observational tool to explore well-being and Self-expression, in the context of interactions, during creative sessions and, second, to facilitate focused conversations with participants by showing them downloaded footage of themselves taking part in a creative session, as I describe later.

Researching people with dementia using video

There have been some attempts to use video when exploring the social worlds of people with dementia. Gallagher-Thompson et al. (1997:347) were one of the first to video-record people with dementia in research. They attempted to capture a "reliable snapshot" of the interactions that occurred between men who had moderate dementia and their wives in their own homes. This research focused more on caregiver interactions, with the aim of reducing caregiver distress than on exploring the meanings of interactions for participants with dementia themselves. Small et al. (1998) video-recorded spontaneous staff interactions with 17 residents in a long-term care unit in order to explore preservation of residents' self. Their study is of value in that it draws attention to how participants indexed self through their nonverbal behaviours. However, while they sought consent from staff and next of kin, they give no indication that they sought consent from participants. This study could also be criticised for its covert approach to data-collection, which involved positioning a video-recorder in the corner of the lounge ceiling and recording interactions for three

successive days. Mayhew et al. (2001) video-recorded five people with advanced dementia to explore, in conversation with a gerontological clinical nurse specialist, their self-awareness and well-being. However, they too give no indication as to whether or how they sought consent from participants. Skovdahl et al.'s (2003) research involved video-recording several care staff showering two residents in two different units which cared for people with dementia, in order to explore whether different interactional styles triggered residents' aggression. This study explored interactions from the perspective of all participants: care staff and people with dementia. However, the process of data-collection raises serious ethical issues. By recording people with dementia naked (from the waist up) and in vulnerable situations, this study could be criticised for infringing on participants' dignity and objectifying them. This reminds us of the sensitive nature of some research and the need to keep participant dignity at the forefront of research.

Taking a more reflexive and inclusive approach, Cook (2002) video-recorded interactions between participants and staff in residential care, in order to explore the impact of the setting on communication patterns. She involved participants in data-collection; by showing them the video-recorder, by consulting with them on where to position it and by showing them footage and including their interpretations of the footage in her findings. Although Cook (2002) tried to record normal interactions, her presence with the video-recorder and in conversation with participants, may have meant that the interactions she recorded were less naturalistic than had she not been there with her video-recorder. In my research, I positioned the video-recorder on a tripod and tried

not to interact with participants during filming; in order to try to capture as closely as possible the types of interactions that took place between OTs and participants during creative sessions. Cook (2002) also showed participants their downloaded footage on the communal television, denying participants privacy. In order to redress this criticism of Cook's study, I used a digital video-recorder and downloaded the footage onto a laptop, which I reviewed with participants in a quiet sitting room. This ensured a higher degree of privacy for participants and was more in keeping with a person-centred approach.

My research aimed to expand the small body of knowledge gained by video methods. It also aimed to build on Cook's (2002, 2003) inclusive approach and Kitwood's (1997) person-centred philosophy by involving participants in all aspects of video data-collection while striving to maintain their dignity and avoid objectification.

As it would have been impractical to gain consent to video-record all who entered the wards, I opted to only video-record creative sessions. This means that, as I used a different method for data-gathering than in the wards, I could be criticised for not having similar data with which to compare interactions in wards and creative sessions. I resolved this issue by writing detailed descriptions of the video footage and analysing it using DCM. By developing data from the video footage which was similar in nature to the data I gathered in the wards, I maintained consistency in the analysis. I will discuss this in more detail later in this chapter.

Reflexivity and video methodology

Video is no more a true representation of life than photography; it too is a technical, social and contextual construction, as its sociological eye is limited by its line of vision and its focal length (Albrecht, 1985) and by decisions, actions and orientations of both participants and researcher (Lomax and Casey, 1998). Pink (2001) advises that ethnographic video-makers need to be aware of how the camera and video-footage become an element of the play between themselves and those they record. Contrary to the idea that the presence of the camera and researcher contaminate the setting by altering participants' behaviour, Lomax and Casey (1998) argue that reflexive analysis of the data can help produce additional insight into the research question. Rather than being seen as a problem, reflexivity is seen as a resource (Banister et al., 2001:13) in which the influences of the situation or person are acknowledged and valued rather than noted as variables, which need to be removed. As such, a reflexive approach to data-collection and analysis is essential.

Calls for reflexivity, acknowledging, as they do, the dialectical influences between researcher and researched, prompt a shift from a realist approach to video which sees it as portraying an objective reality (Collier, 1967) to the idea that video produces yet another representation of the world (Lomax and Casey, 1998). A constructionist approach to ethnography sees this as unproblematic, as constructionism recognises the co-construction of "reality" and acknowledges the place of reflexivity in the research process. However, while Cook (2003) suggests that the distorting influence of the camera becomes just one more aspect of the research process to reflect on, I sought to minimise my influence

on the creative sessions by trying not to engage with participants in order to promote the type of interactions that regularly took place between participants and OTs.

Ethical issues and video-recording

Video-recording vulnerable people, as I did in this research, raised several ethical issues, which I had to consider carefully. In the following sub-sections, I will discuss the potential for harm surrounding inappropriate use of video-footage and how I ensured that participants did not come to psychological or physical harm during recording.

There is a balance in such research between the need to protect vulnerable participants while ensuring that the demands placed on researchers are not so restrictive as to preclude valuable research (Iacona and Murray, 2003). I have tried to negotiate this balance by adhering to ethical requirements while maintaining an inclusive stance.

Publication of images

Cook (2003) draws attention to the fact that researchers have failed to consider the implications for people with dementia when visual images of them are published. Publishing photographs or still images of people with dementia is widespread in certain journals and there is no evidence as to whether consent has been sought for their use or whether the images depicted are actually of the research participants. These images have the potential to objectify research participants and it is questionable to what extent such images add to findings. In

order to adhere to the principle of non-objectification, I include no visual stills in my thesis.

Unintended recording of non-participants

There was always the possibility that I might inadvertently record non-participants if they walked into the frame while I recorded creative sessions. I resolved to avoid this by positioning the camera so that only the participating group would be framed. I monitored the activities of any nearby non-participants and took evasive action when necessary. If a non-participant did walk in front of the camera, I repositioned it so that the non-participant was not filmed, I tried to guide the non-participant away or I turned off the camera until the non-participant had moved away. By considering beforehand, the different options I could take in this eventuality, I was able to take quick action to ensure that I filmed no non-participants.

Psychological harm to participants

The presence of the camera had the potential to cause distress or discomfort to participants: those with dementia and OT staff. While Gallagher-Thompson et al. (1997:350) found that the caregivers in their study grew more comfortable with the presence of the camera to the extent that they stopped thinking about it, they make only brief reference to participants with dementia; stating only that the camera was usually a "non-issue for the patient". Skovdahl et al. (2003) contend that while the caregivers in their study were aware of being video-recorded, this did not negatively affect their interactions. However, they make no mention of how participants with dementia responded to the presence of the video-recorder. Cook (2002), in a more detailed account, found that participants

interacted with her as she held the camera, suggesting that they were comfortable with its presence.

Dewing (2002) advocated the use of props in explaining a study and when gaining consent from people with dementia and I will describe how I followed this process in the next chapter. In my study, this approach also served to familiarise participants with the camera, thereby reducing anxiety and ensuring that their experiences in the creative sessions remained relaxed. At no stage during filming did any participant express discomfort.

After each session, I thanked the participants whom I had filmed and chatted with them. I also asked the OTs how they had felt about the session. For example:

> *I spoke with Eddie and Nina to check how they felt about the session and the process of being filmed. They were both fine, saying that they didn't feel too self-conscious about it.*

Because I had to strike a balance between debriefing with the OTs and getting back to mapping the participants, my conversations with them were shorter than I would have liked. However, I felt that our planning meetings (which I describe in the next chapter) prior to starting the research had been useful in forcing me to confront potential problems before they arose. I am sure that these initial meetings fostered the collaborative and open spirit in which the creative sessions were recorded and they ensured that we all experienced the filming

process as relaxed rather than intimidating. This shows the value in engaging openly and honestly, with all participants before fieldwork begins.

Physical harm to participants

The final ethical issue I had to consider was to ensure that participants or non-participants did not come to physical harm during video-recording. I had to consider that they might bump into the equipment or trip over the flex. The camera had a zoom lens and an additional microphone, which meant that I could position it in the corner of the room out of harm's way and still capture the interactions that took place. By sitting on the floor beside the tripod and monitoring the movements of participants and non-participants, I was able to deflect anyone who came too close. No-one came to any harm.

Justifications for video-recording creative sessions

I justify using video as a method for data-collection on several grounds.

This study aimed to capture nuances and subtleties of interaction. Data gained from video-recordings were far more detailed than those gained solely from interviewing or using systematic observation methods such as note-taking or coding into pre-defined categories as in DCM. The use of a video-recorder was an innovative way to capture, examine and re-examine such nuances during creative sessions, and was particularly important in trying to understand the experiences of those with little verbal communication.

The capacity to download video-footage onto a laptop and show it to participants allowed their direct input into the research; by providing their own

interpretation of what was happening. The prompting effect of watching the downloaded footage could be the only means for some people with dementia to contribute their ideas and meanings, and for this reason, the use of the video-camera was vital if their opinions were to be heard first hand and not through my interpretations alone.

This study builds on Cook's (2002) call to find other ways of including those with dementia in research, particularly those who have difficulty in articulating their needs, wishes and opinions for themselves, although as I have already discussed, for practical reasons I opted only to record in the relatively private space of the creative sessions.

Video-recording creative sessions

In ward 1, Michael, the art therapist facilitated the creative sessions, which he held in the dining room after the 11 o'clock cup of tea. Having set the tables with paints, paper, brushes and jars of water, Michael would approach the men and women and ask them if they would like to stay and paint. Of the three whose next of kin had given approval, only Edward took part regularly and Florence took part, although unsuccessfully, once. Although Nora used to take part regularly, her mood had deteriorated over the seven weeks I was in the ward and she declined Michael's invitation each time saying: *'Oh, maybe next week'*. On one occasion, she sat at the table, but was so disengaged that I did not approach her to film her.

On the one occasion, that Florence gave permission to be filmed:

> *She watches me place it* (the camera) *on the tripod, but by now she has lost interest in painting and she sits looking vaguely around her and vaguely at the brush in her hand. Michael goes to her and encourages her to paint, but Florence responds with: 'it's a load of rubbish'. Shortly afterwards she removes her apron, and stands up. I stop the camera.*

I felt uncomfortable that I had video-recorded Florence looking so disengaged. Later, I wrote in my fieldnotes:

> *Initially I thought that the footage was of no use. It was of no use in telling me whether creative sessions are beneficial for her, but maybe it can tell me something else. Maybe it can tell me of the isolation a woman with dementia can feel, in a setting where staff are not trained to work that extra bit in order to reach her.*

Later again, as I reflected on the footage, I wondered whether Florence would have engaged more positively in the creative session, had she received more supportive interaction from Michael. This, and another insight from ward 2; in which Mary tried to engage with ward staff but gave up, in the absence of recognition by them of her eagerness to engage, sowed the seeds for what was later to become the central idea of the thesis. Thus, what seemed to be of more importance for participants was not necessarily the creative sessions, but the opportunities for positive, supportive interactions that they afforded. I explore these ideas in chapters 6 and 7.

In wards 2 and 3, two OT staff usually facilitated the creative sessions. Again, they were mostly held in the dining rooms, but this time in the afternoons. The OT staff would approach the men and women and invite them to join them in painting or collage work. Once participants were settled at the table, I would approach them in turn and seek their consent to be filmed as described in the next chapter. When I received their consent, I put the camera on its tripod in the corner of the room and turned it on. I would sit on the floor beside the camera with my notepad on which I wrote comments or observations. I would regularly check the LCD screen to make sure that only my participants were in view and also to remind participants of my and the camera's presence. Occasionally a non-participant would join for a short while and on these occasions, I was careful to adjust the focus to exclude him/her from the frame.

I decided not to video record Hannah's final time at the creative session as she had fallen a few days previously and had extensive bruising and swelling to her face. I felt that video-recording her was too intrusive so I mapped her time at the session instead. On reflection, I could be challenged for being maternalistic and for reflecting onto her, my wishes not to be recorded had it been me with such bruising. In defence, my decision not to record her stemmed from a desire not to objectify her facial distortion and not to add to her distress by seeking permission to record her.

Filming the creative sessions was relaxed and fun. I always wanted to join in the sessions, but of course, I couldn't. Sometimes Hannah and Isabel would wave

or smile at me; indicating their acceptance of me and my camera. One time Isabel:

> *… attracts my attention by whistling quietly to me and saying: 'isn't it good?'*

Another time Bill expressed his acceptance of the camera by:

> *… performing for the camera and occasionally waving at me.*

In ward 3, these were my best times, as it was here that I saw the men at their most relaxed; receiving sustained positive interaction. Here, I too could relax.

Interviewing people with dementia

The final method for data-collection involved showing participants footage of themselves during a creative session, which was downloaded onto a laptop, and seeking their consent to audio-record the ensuing conversation. This was a less structured approach than an interview, but I anticipated that the prompting effect of the video-footage might add direction to the conversation. I will first discuss how researchers are increasingly trying to involve people with dementia in research, before describing my own experiences of engaging in focused conversations with participants.

Informal interviews and conversations are widely used in ethnography as it is through speaking with informants that insight into ways of living are gained. As Robinson (2002:107) says, it can be powerful for people with dementia to know that they are contributing to an understanding of a disease in which "no one but us knows what it's really like".

In response to calls to "hear the voice of people with dementia" (Goldsmith, 1996) and to focus research on the "*individual* with dementia" (Downs, 1997), researchers have sought ways to include people with dementia in the interview process. Tappen et al. (1999) tape-recorded conversations with people with moderate to severe dementia in order to elicit references to self. These appeared to be open ended, unstructured conversations, which were analysed to identify certain themes rather than attempting to seek the views of participants. Taking a more formal approach, Proctor (2001) tape-recorded semi-structured interviews with four women to elicit their views on the day hospital that they attended. Pearce et al. (2002) interviewed men in the early stages of Alzheimer's disease to explore how they managed a changing sense of self. Cook (2002) showed participants video-footage of themselves engaged in conversation and audio-recorded their views in order to add their input to her analysis. McColgan (2004) attempted to interview residents in a nursing home to explore the culture of the nursing home and how this reflected and reinforced dominant conceptions of dementia. Hulko (2004) used photographic prompts designed to stimulate responses to questions, which aimed to explore participants' experiences of being marginalized in terms of ethnicity, gender and class while also living with dementia.

The strength of these studies lies in researchers' attempts to understand participants' social worlds from their own perspectives, using formal and informal interviews with their participants. My study also aimed to give participants with dementia a voice in the research by using downloaded video-

footage shown to them on a laptop to aid them in our conversation. This was not entirely successful, as I shall explain below.

My experience of focused conversations with participants

McKillop and Wilkinson (2004) stress the importance of building up a relationship between interviewer and interviewee. Cook (2002) recommends that, in order to avoid objectification of participants and their experiences, their involvement where possible to provide their own analyses and interpretations is essential. My research aimed to follow these recommendations. By building up a prior relationship with participants before showing them downloaded footage of themselves taking part in a creative session, and by seeking permission to audio-record conversations with them, I hoped to give them the opportunity to freely articulate their own opinions on the creative sessions. As seen in Table 2 (page 83), only three participants took part in this stage; Isabel in ward 2 and Bill and William in ward 3.

In ward 1, I decided not to interview Edward, as I knew that he could become stressed when required to communicate verbally and when required to engage in close proximity. For other participants, I wanted to select footage that I felt was clear enough to see properly, that showed participants looking well and in which only the participant featured. This meant that I waited until after the last recording session before approaching participants. The delay in seeking their views was too long for some participants: Hannah died before I finished in ward 2 and Mary's cognitive abilities rapidly deteriorated soon after the final recording session and she became anxious when required to carry out any tasks. In ward

3, John's deteriorating physical condition meant that he too was unable to take part in this stage.

In ward 2, Isabel gave me her consent to show her some footage and to audio-record our conversation. The conversation with her did not go as expected because she identified the woman in the footage as her mother and reminisced about her fondly. When I told Isabel that the woman was actually her, she insisted that it was her mother. I did not try to persuade her otherwise because I felt that imposing my viewpoint might damage her perception of how things were for her. Isabel then spent the next 20 minutes animatedly talking with me about her mother. This episode highlighted for me the importance of being able to resist the urge to make research work for the researcher and the importance of flexibility in research. It also reminded me of the contested status of "truth".

In ward 3, the conversations with Bill and William were more successful in informing me of their views. On both occasions, the conversations took place in a quiet sitting room, where we could concentrate without fear of being disturbed. During the conversation with Bill, a staff nurse came into the room and looked at the footage for a few minutes while Bill was talking with me. I was concerned that the presence of the nurse might be breaching Bill's confidentiality, but as Bill included the nurse in the conversation, I decided not to intervene. Bill's conversation was disjointed at times and I worked hard to bring him back to the topic of the creative sessions, all the while hoping that with careful listening of the audio-recording, I would glean some level of understanding of his opinions on the sessions.

William's conversation was more straightforward and easier to follow, although, as his speech was difficult to understand, I found myself repeating what he had said to confirm that I had heard him correctly. This followed Sabat's (2001) idea of indirect repair; in which the listener rephrases the speaker's words in order to check her understanding of the speaker's meaning. William, like Bill, was interested in the equipment and seemed pleased to be asked for his opinion. I felt that using downloaded footage gave a focus to the conversation and prompted a more specific reminiscence about the creative sessions.

Although there were only three participants, this stage demonstrates that it is possible to engage in focused conversations with people with more advanced dementia, although it also highlights the need for sensitivity on the part of the researcher to the perceptions of those being interviewed. This stage contributed to my study by enabling me to ascertain their views and by contributing their voices to the data.

Construction of data

In this section, I will give an account of how I constructed data sets from the different methods used and how I attempted to maintain consistency throughout the data sets. I will describe how I constructed data for analysis from fieldnotes derived from non-participant observation, DCMs, video-recordings and focused conversations.

Fieldnotes

My fieldnotes provide a thick description (Geertz, 1973) of what I saw and heard in the wards; written as soon as possible after I saw or heard something

interesting. They also record interpretations, impressions and feelings that I experienced during my time in the wards. The raw fieldnotes, written in a notepad tied round my waist, were sketchy and required processing; they needed to be made sense of, expanded, edited and typed up in my fieldwork journal. Every evening when I got home, I reviewed the raw data and typed up detailed fieldnotes; using black font for my observations and red font for my feelings, notes and impressions. In this way, I could keep a separate, yet parallel, record of fieldnotes and reflections (see Appendix 7 for a short extract from my fieldnotes).

Because my focus was on types of interactions experienced by participants and their responses to such interactions in terms of well or ill-being and Self-expression, these concepts informed the bulk of my fieldnotes. Thus, Kitwood's (1997) elements of malignant social psychology and positive person work, and Sabat's (2001) aspects of Selfs 1-3 added structure to my observations and fieldnotes. In this way, I could more easily engage in data reduction (Miles and Huberman, 1994), in which I selected, focused, abstracted and transformed the data in my fieldnotes, in order to begin to analyse them.

DCM

Following each day's map, in which I amassed 144 units of data for each participant (five-minute recordings of behaviour category codes and well or ill-being values over six hours), I input the raw data into specially designed Excel spreadsheets. From here, I was able to calculate individual and group WIB values and behaviour profiles (see Appendices 8 and 9 for an example of each).

This gave me quantitative data on participants' well-being levels which I could later interrogate and compare between participants and across wards.

I wrote a summary of each person's map and included it, along with my own reflections, in my fieldnote journal. I filled out Individual Care Summary forms for each participant (Appendix 5), which indicated how each participant fared in terms of well or ill-being in relation to the interactions they experienced from ward and OT staff. I also filled out a Group Care Summary form for each ward after each map, which illustrated the quality of care in the wards (see Appendix 10 for an example). By developing textual fieldnote data along with quantitative DCM data, I aimed to maintain consistency in my documentation of participants' social worlds.

Video

Every evening, after video-recording a creative session, I downloaded the video-footage from the digital video-recorder into a file in my computer. I viewed and reviewed the footage, stopping and starting frequently to write descriptions of what I observed in the sessions. I documented the types of interactions that occurred between participants and OTs, transcribed audible conversations, noted visual expressions and actions of participants and incorporated these into my fieldnotes. I also carried out DCM on the footage, in order to later slot the relevant timeframes into the DCM spreadsheet. By constructing video-data using fieldnotes and DCM methods, I ensured that the data for later analysis remained qualitatively and quantitatively consistent with other data.

Focused conversations

Construction of data from the focused conversations involved repeated listening to the tapes and transcribing our conversations verbatim. As with the other data sets, I constructed a textual account of participants' views on creative sessions, which I could analyse in a manner which was consistent with other data.

Analysis of data

Following Silverman (2005) I address concerns about the validity of my research (whether I have actually measured what I purport to measure). Silverman (2005) suggests using constant comparison: finding other cases in the data with which to test out a provisional concept. I used constant comparison by searching the text for elements of malignant social psychology, positive person work and aspects of Self, and in my search for recognised and supported Self along with their counterparts, as described below. Silverman (2005) also suggests incorporating simple quantitative data within ethnographic research in order to validate the impressions obtained from ethnographic data. By using DCM, which provided quantitative data (along with qualitative data), I have strengthened and added validity to the thick descriptions in my fieldnotes. Table 3 in chapter 6 and Table 4 in chapter 7 (pages 209 and 286 respectively) also validate my initial impressions by providing useful quantitative data to support ethnographic data.

I follow Mason (2002) in considering the theoretical generalizability of my research (the ability to make inferences from a small sample to the wider population). Mason (2002) identifies different logics whereby researchers can claim theoretical generalization, which include widening the resonance of one

study in order to ask about the lessons for other settings, and building and extending on existing theory and research. I aim for theoretical generalizability by using these two strategies throughout my thesis.

Analysis of qualitative data requires that fieldnotes, interview transcripts, texts and observational data be systematically scrutinised in order to identify patterns, themes, categories or illumination of people and practices. This usually takes place on an ongoing basis and may be achieved through the use of "grounded theory" (Glaser and Strauss, 1967) or through a less inductive approach in which the researcher reads through and beyond textual and observational data and critically interprets it in the light of the "intellectual puzzle" s/he set out with (Mason, 2002:18). As I set out to answer specific questions, I took the latter approach in this research, as I will describe below.

The focus of the research shifted as I progressed through fieldwork and analysis; from seeking a relationship between creativity, well-being and Self-expression to one that recognised the importance of interactions in nurturing or undermining well-being and facilitating or stifling Self-expression. Hammersley and Atkinson (1983:175) put this reassuringly:

> *Ethnographic research has a characteristic "funnel" structure, being progressively focused over its course… over time, the research problem is developed or transformed, and eventually its scope is clarified and delimited and its internal structure explored. In this sense, it is frequently only over the course of the research that one discovers what the*

research is really "about", and it is not uncommon for it to turn out to be about something quite remote from the initially foreshadowed problems.

I will discuss a further shift in focus as my analysis progressed in the next sub-section.

Analysing fieldnotes

My fieldnotes were to some degree "theoretically saturated" (Silverman, 2005:158); that is, my writing was already grounded in the person-centred approach and loosely informed by the Selfs1-3 framework. In order to remain as open as possible in my observations and writing throughout fieldwork and in order that other theories did not "crowd" my thinking, I decided to wait until the end of fieldwork before examining and analysing fieldnotes.

Having made an initial literal reading (Mason, 2002), I progressed to making interpretative and reflexive readings; I tried to read through and beyond the text, while also locating myself in the data; acknowledging my role in data-generation and interpretation, as I reflect on in the following chapter.

While I initially used the more traditional paper and coloured pens method for understanding and analysing the data, I quickly realised how difficult it would be to manage it systematically. I resolved this by importing all the fieldnote data into NVivo7, which is the latest development in qualitative data-analysis and management; enabling the researcher to code and analyse qualitative data such as interview transcripts and fieldnotes. NVivo7 was immensely useful in keeping track of a large quantity of data, for interrogating it, for linking DCM

data with fieldnotes and for quickly accessing original text to support and challenge the development of concepts.

Using symbolic interactionism and social constructionism as theoretical frameworks to inform my analysis, I sought for and coded interactions that I observed between participants and staff; both ward and OT staff. I used Kitwood's (1997) 17 elements of malignant social psychology and his 10 elements of positive person work as categorical frameworks as he has already identified and defined these elements of interaction. This was a useful starting point for analysing interactions that I observed. Here, from my fieldnotes in ward 3, is how I coded some frequently occurring elements of malignant social psychology. In this passage, I coded *disruption*, *objectification* and *outpacing* as initial free nodes[3]:

> *John has been sleeping since I came here nearly two hours ago. A care assistant approaches him, simultaneously calls out to him and takes his hands to pull him from his chair. John wakens up with a start and finds himself pulled into a standing position* (disruption, objectification)*. He staggers sideways. "Oops" says the care assistant before pulling him along the room, up the corridor and into the dining room* (outpacing)*.*

I identified and coded all 17 elements of malignant social psychology with varying degrees of severity and six of the 10 elements of positive person work. Having developed and defined free nodes, I grouped similar nodes together into

---

[3] A free node is a 'stand-alone' node that has, as yet, no clear logical connection with other nodes. You can gather relevant free nodes together into a tree node.

tree nodes[4]. For example, I grouped all 17 elements of malignant social psychology into a "damaging staff interactions" tree node and elements of positive person work as a "positive staff interactions" tree node (see Appendix 11 for all tree nodes and their constituent free nodes).

I also sought for and coded participants' verbal and visual expressions of Selfs 1-3; following Sabat (2001; 2002; 2005). Taking a symbolic interactionist stance, I "took the role of the other" to imagine and define situations as though I were a participant. When coding for Selfs 1-3, I used my fieldnotes to remember, re-experience and empathically understand what aspect of Self participants might have been expressing. I tried to re-experience the context during which Self was expressed, tried to re-experience the emotional content of expression, both for participants and for me and tried to remember bodily expression, particularly in visual expressions of Self. I constantly tried to position myself in participants' shoes, in order to come as close as I could to understanding what aspect of Self they were expressing. This was sometimes painful, as I re-experienced participants' fragility and anxiety but was a crucial part of the analytic process. Here, for example, from my fieldnotes in ward 2 is what I interpreted to be visual expressions of Self:

> *I sit for a long time with Kate while she chews her gums and blinks heavily. Every so often, she looks at me and gives me a beaming smile. I talk to her, telling her who I am, that I am here to visit and hope to see her often… On a few occasions, she brings her hands to her hair, smoothes them over it and carefully tucks it behind both ears.*

---

[4] Tree nodes are organised in a hierarchical structure, moving from a general category at the top to more specific categories at the bottom.

In this extract, I interpreted Kate's act of smoothing her hair and tucking it behind her ears as a visual expression of Self 2; awareness of her physical characteristics, and her smile to me as an act of greeting; a social Self 3.

Although I used Sabat's framework as a guide for identifying different aspects of Self, I revisited and refined the coding as my empathic understanding deepened. For example, on reflection, I recoded an initial *expressing pride* free node as an *expressing pride/Self 2* free node to reflect that an expression of pride is an expression of Self 2. I concluded that the *exerting control* and *exercising control* nodes were also expressions of Selfs 2 and 3. Similarly, I pondered over the *seeking occupation* node and concluded that this could also be an expression of Self 3. Here, from ward 1:

> *Florence is not happy. She has been pacing up and down, moving cushions from the little sitting room out to the corridor, she has been taking the covers off the cushions, removing packets of incontinence pads from the toilet and spreading the pads on the chairs down the end of the corridor…*

Here, it seems that she is trying to alleviate her boredom and restlessness by working; by tidying and arranging cushions and incontinence pads. I interpreted this as Florence seeking some purposeful role in her life; seeking to enact Self 3, and thus I coded it as a *seeking occupation/Self 3* free node.

I then began to look for associations between interactions, well/ill-being and Self-expression. I began by coding participants' responses to interactions in

terms of their well/ill-being and Self-expression. I grouped types of staff interaction according to how participants responded in terms of well/ill-being and Self-expression. For example, I developed tree nodes such as "No interaction", "Limited interaction" or "Abusive behaviours" to reflect the differing impact of elements of interaction on well-being and Self-expression. I then began to seek patterns and differences in interaction and well-being between and within wards and creative settings and between participants, and realised that those least able to initiate or sustain interaction were also the most isolated, as I illustrate in chapter 6.

Analysing the data was a voyage of discovery; the deeper I went, the more questions I asked, the more I was able to seek and make connections. In response to emerging questions, I re-examined the text to find examples or counter examples to support or elaborate emerging understandings. For example, one day, as I ruminated over my fieldnotes and reflections, I realised that there were many references to ward staff not recognising or supporting participants' attempts at Self-expression, particularly their enhanced Self-expression following creative sessions. It occurred to me that this was a potentially important point, which needed further inspection. Here, from a memo is my documentation of this realization:

> *When participants return to the wards, staff do not seem to notice their enhanced Self-expression; they do not seem to support Self. I will look for other instances of unsupported Self. Do I need to look for instances where staff don't recognise Self? ...this would be an "unrecognised Self"*

> *node. If staff don't support Self, does this mean that they haven't recognised Self in the first place?*

I searched the text to find other instances of "unsupported Self", then for "supported Self", "unrecognised Self" and "recognised Self". I sorted each node in terms of which aspect of Self was recognised, unrecognised, supported or unsupported, and by whom in order to explore whether my hunch was correct. I counted each type of interaction and present the findings in Table 4, in chapter 7 (page 286). This quantitative analysis, which provides new and important insight into the social worlds of participants, has become the basis of this thesis.

Difficulties with analysing Self

Analysing the data raised several questions regarding Self, which I will briefly discuss.

Coding for Self-expression became increasingly complex, as I tried to map behaviours and expressions onto the framework. I questioned what aspects of behaviour were expressions of Self, and latterly, whether all behaviours could be expressions of Self. If all behaviours could be expressions of Self, how appropriate was it to try to pigeon-hole expressions into such a framework? Is Sabat's framework too simplistic to capture the complexities of Self-expression?

I also wondered where a spiritual or meditative Self would fit into the framework. This particularly applied to Kate, who spent long periods stretched out in her chair; hands behind her head, seemingly content in her own mental place. This

seemingly meditative, or gerotranscendent contemplative state (Tornstam, 1997), which I mentioned in chapter 1, does not fit easily into the framework.

What about the Self of the body? Sabat's framework relies on some level of cognition or awareness, but I wondered about the 'beingness' of one's body as expression of Self. Paul, particularly seemed to exemplify the state of being that one is, and perhaps licked the table and sucked his thumb as a reminder to himself, and indirectly to me, of his own bodily existence. After I finished in ward 2 and returned to visit, I observed that Kate now sat, not only in her own world, but also sucking her thumb and I wondered whether she was also trying to connect with her bodily self. This resonates with Kontos's (2005) idea of an embodied self; in which selfhood is grounded in corporeality, which I discussed in chapter 3.

I raise these questions only to highlight the complexity of seeking and analysing Self-expression in others (particularly visual Self-expression). I conclude that, for the purposes of this study, I can only try to work within Sabat's framework, while acknowledging its limitations.

Analysing DCM data

Data arising from DCM is both quantitative and qualitative and can be analysed to provide insight into participants' social environment, and their responses to the environment in terms of behaviour and levels of well/ill-being. Following each day's map, I input the raw data onto a specially designed Excel spreadsheet. I calculated individual and group WIB values and wrote Individual and Group Care Summaries as mentioned previously.

Graphic representation of these analyses was also possible using Excel (see Appendices 8 and 9 for examples of individual and group WIB values and behaviour profiles). As well as calculating participants' overall WIB values, I calculated their WIB values for two hours and one hour before the creative session, their WIB values during the session and for the first and second hours following the session (see Appendix 12 for participants' individual WIB values before, during and following each creative session).

Having imported the detailed written accounts of each day's map into NVivo7, I searched the data for interaction types that participants experienced (following Kitwood, 1997), their well/ill-being levels (derived from their DCM data) and expressions of Self (following Sabat, 2001). Below, is an extract from my fieldnotes of one of Paul's DCMs, in which there is thick ethnographic description, DCM data in terms of BCCs and WIB values (see Appendix 2), and documentation of interaction types, in this case elements of malignant social psychology:

> *Paul sits at the table, licking it over and over; W+1 for two time frames. A care assistant puts a beaker of milk on the table in front of Paul and he tries to drink it, but a lot of it spills onto the table and over his apron. He tries unsuccessfully to drink from the beaker; F-1. Then he manages to lift the beaker up high enough to take little sips: F+1 for two time frames. The charge nurse comes and feeds Paul. Over and done with in five minutes: P+1. He still has the beaker of milk in front of him and he is lifting it up and down, up and down, but not managing to drink from it. When he does manage a mouthful, he chokes and starts to cough: F-1.*

Shortly after, a care assistant comes and brusquely takes off his apron, takes away his beaker and cleans the table; objectification. She admonishes him for making a mess; P-1, infantalization, accusation.

By linking fieldnotes and DCM data, as in the extract above, I was able to document types of interactions that participants experienced and to tease out their responses to such interactions; in terms of their well/ill-being or Self-expression. I was also able to support my findings with descriptive statistics available in DCM (WIB values and behaviour profiles). In the extract above, which spanned 40 minutes, Paul initially experienced minimal task-oriented care, with no meaningful supportive interaction and a consequent deterioration in his well-being. His only extended contact was with the charge nurse and was purely task-oriented with no attempt to engage meaningfully with him. During this time he was neither in well-being nor ill-being. His unsuccessful attempts to drink from the beaker went unnoticed and unsupported and when he choked his WIB value dropped. The final encounter with the ward staff was task-oriented, brusque and negative. Although Paul would not have heard her admonishment, as he was deaf, her brusque manner in taking off his apron, taking the beaker from him and quickly cleaning the table warranted the minus value (P-1).

Analysing video-footage

After each creative session, I downloaded the video-footage from the digital video-recorder onto my laptop and viewed it several times. Stopping and starting the footage; I wrote detailed descriptions of what I saw and heard, imported them into NVivo7 and coded them for different elements of interaction, well/ill-being and expressions of Self. In order to maintain analytic consistency, I

also analysed the footage using DCM, although this was not always satisfactory, as I will discuss below.

Limitations with coding video-footage

I became most aware of DCM's limitations when analysing the video-footage from the creative sessions. There was a wide variety in participants' attendance times at the creative sessions and therefore the length of video-footage obtained ranged from five to fifty minutes. In DCM terms, some of these time scales are minute and if analysed following DCM rules, would produce minimal data. However, in interactional terms, five minutes can be a long time. The ability to review the video-footage allowed me to identify fleeting subtle actions and interactions, which seemed to be of importance for the participant, but which, I could not adequately code following operational rules.

For example, during the first timeframe of a session with Edward, who was usually reticent and tense, he initiated contact, which was mirrored by H, the care assistant who was assisting him at the creative session. There then followed reciprocal smiling and engagement from both parties which, while only lasting 19 seconds, was a significant length of time for Edward. There followed a few minutes where he watched what she was painting with interest, followed by a short spell during which he replaced the lid of a pastel box and positioned it on the table in workmanlike fashion. Within this five-minute timeframe, three significant events occurred: he initiated and managed to sustain an interaction; he took a sustained interest in the activities of the care assistant and he engaged in work-like activity. When using DCM, I could not code these subtle

yet significant events within the one timeframe and had to make a decision as to which of the several possible codes to use.

On another occasion, in ward 2, I noticed a significant but subtle change in demeanour within Hannah's video-footage. She expressed a self-assurance and confidence while painting that I did not see in the ward. She clearly engaged in E (expressive or creative activity), but there was also an element of L (performing work or work-like activity) as she had been an artist all her life, and there was the emergence and expression of a past Self for which there is no BCC. According to operational rules, I had to make a decision to apply one code to that timeframe, thereby not capturing the complexity of her Self-expression. Here, from my DCM notes is a reflection on the difficulties I had when mapping Hannah's footage:

> *Looking at the video-footage, I am frustrated at the lack of subtlety of the coding. Within one timeframe, Hannah could be gesticulating a shape to draw, then drawing, pausing to admire or choose a colour or communicating with her eyes. I want to include all these behaviours, but can't.*

Had I relied solely on DCM as an observational and analytical tool, I would have missed such subtle and complex behaviours and expressions. The value of video-recording, in conjunction with carrying out DCM and writing detailed fieldnotes, meant that, when it came to analysing the data, I could build up a multi-dimensional account of participants' experiences in the creative sessions.

Analysing focused conversations

I will briefly outline my analytic stance towards interview data, before describing how I analysed the transcripts.

Analytic stance towards interview data

Silverman (2001) points out that there are three principle ways to view interview data: positivist, emotionalist and constructionist.

Positivism is the longest-established social science perspective. Positivists argue that "facts" exist in the world and can be discovered through interviews based on pre-tested, standardized questions. The reliability of such research is achieved by adhering to standardized interview protocols. Interview data are seen as corresponding to the "world out there". Positivism is contested by emotionalists and constructionists, who question the value of data derived from standardised, survey-style interviews.

Emotionalists seek, not to obtain objective "facts", but to elicit authentic accounts of subjective experience and they treat emotions as central to such experience. In contrast to the structured protocol of positivist interviews, emotionalists aim, through open-ended or non-directive interviews, to become emotionally involved with their respondents in order to gain an intersubjective understanding of their "authentic reality". Here, too, data are seen as representations of respondents' worlds.

In contrast, constructionists are interested in documenting the ways in which respondents' accounts are part of the world they describe; recognising that

people's social worlds are far more complex than most positivists would contend. Constructionists argue that interviewer and interviewee are always actively engaged in constructing meaning; thus, knowledge is mutually constructed. Most constructionists also want to explore what respondents are saying as well as how they say it. As Holstein and Gubrium (1997:127) suggest:

> *The analytic objective is not merely to describe the situated production of talk, but to show how what is being said relates to the experiences and lives being studied.*

In carrying out and analysing the two focused conversations, I veered towards a constructionist position, which fitted more closely with my epistemological stance; that knowledge and evidence are contextual, situational and interactional.

Analysing interview transcripts

The focused conversations produced minimal data; constituting only 12 pages of transcript. However, I still needed to make sense of them.

I analysed Bill and William's conversations shortly after engaging them in focused conversation. I read and re-read the transcripts; trying to understand the, sometimes, disjointed nature of our conversations. I attempted to engage in a systematic, rigorous consideration of the data and marked out; using coloured pens, themes and concepts (Fielding and Thomas, 2001) that seemed to reflect participants' opinions on the creative sessions. From both their conversations, I identified *occupation, structure* and *fun* as important components of the creative sessions and, when I compared these components with the data from my

fieldnotes and video-footage, they seemed to support the understanding I had begun to gain.

Management of data

In accordance with ethical requirements, I stored signed consent forms and all the hard data: DCM spread sheets, video tapes, interview tapes and transcripts in a locked filing cabinet in my office at the University of Stirling. I stored fieldnotes, DCM data, downloaded video-footage and transcripts for analysis on a laptop to which only I had access through an individualised password.

Conclusion

In this chapter, I have linked my epistemological and theoretical positions with my choice of an ethnographic methodology. I have discussed the choice of research setting, and the process of gaining ethical approval. I have described and justified the methods I used and have discussed each method, particularly in relation to ethical research with people with dementia. Finally, I have described my own experiences of data-gathering, how I constructed data sets for analysis, and how I analysed and managed the data.

In the next chapter, I will use fieldnotes to describe the three wards and introduce the 14 participants and OT staff. I will describe in detail how I sought consent from participants, before reflecting on how I may have changed the research setting and how it impacted on me emotionally and psychologically.

Chapter 5: The wards, participants, consent and reflections

Introduction

In the first section of this chapter, I use fieldnotes to describe the three wards within Moorhills Hospital in which I carried out fieldwork and I identify the general staffing levels on each ward. I use information from casenotes, from next of kin and from conversations with participants themselves to develop participants' biographies (see also Appendix 1). I also introduce the occupational therapy staff and art therapist. I have anonymised all names and changed certain details. For reasons of anonymity, I will not describe the hospital.

Next, using thick ethnographic description, I give a detailed account of how I sought consent from all participants, with particular emphasis on demonstrating how I gained ongoing consent from participants with dementia.

Finally, I reflect on the process of fieldwork; on how I will have changed the research setting and how it impacted on me emotionally and psychologically. I show that, while ethnography is not always a comfortable experience, such "emotional danger" (Lee-Treweek, 2000) can add enormous depth to an understanding of participants' social worlds.

The wards and participants

Ward 1: the ward environment

Ward 1 is a mixed gender 20-bedded ward for those who are awaiting transfer to long-term care, although some have been here for up to two years. Ward 1 is a locked ward; staff can enter and leave with their own key and visitors ring a bell at the front door for entry, but patients are unable to leave of their own volition. During my time at the hospital, I had a key so I could come and go as I pleased. The ward was quiet when I was there, with only 11 of the 20 beds occupied.

The first impression of Ward 1 is good; it is relatively brightly lit and there are pictures on the walls. From the front door, one goes down a long corridor to a central lounge area, which is really just a widening, to the right, of the corridor. The lounge area is carpeted and is enclosed by armchairs facing onto large curtained windows. There is a television in a corner and beside this is a low cabinet on which a sound system and some ornaments sit. There are also armchairs lining the far left hand wall opposite the lounge area. This is where many of the patients sit. The staff office looks onto the lounge area.

Further down the corridor, on the left are three four-bedded rooms, which are kept locked, unless access is required by ward or cleaning staff. They are small and dull with few personalizing items. The staff cloakroom and a toilet are next to the bedrooms

On the right, near the lounge area, is a little bright comfortable sitting room and, further down the corridor are locked storerooms. At the end of the corridor is a window looking onto trees and grass and down here there are some more armchairs.

Towards the front door is the dining room, which is bright and spacious; with six round laminated tables which seat four people each. Next door is the kitchen and, beyond that, a sluice room. Round a corner are two more bedrooms and another bathroom/toilet. The only rooms that are unlocked are the little sitting room and the two toilets. All the other doors, including those to the bedrooms are locked.

I very quickly became aware that a dominant feature of the ward was the noise of banging doors. Whenever staff opened a door; to a bedroom, the office, cupboards etc. they let them slam behind them and those nearby often jumped at the noise. Here, from my DCM notes is a typical entry:

> *Suddenly a door crashes loudly, Nora jumps, so do I.*

And here, from my fieldnotes is what I wrote after a particularly noise-filled day:

> *There is a pervasiveness about these banging doors. The only doors that are unlocked are those leading to the toilets and the little sitting room. All the bedroom doors are locked, the kitchen, the sluice, the office, the staff room, the cupboards, the front entrance and the back door that the staff use. There are lots of doors that the staff unlock frequently, and every single one of them bangs shut.*

The ward staff

I seldom saw the charge nurse, as she had duties elsewhere in the hospital. On each shift, a trained nurse was on duty. In the morning, he/she was accompanied by up to five care assistants and up to two student nurses on placement. In the evening, the staff nurse was accompanied by three or four care assistants and one or two student nurses. There was also a laundry assistant and a domestic on every day. Sessional staff; for example a manicurist and a hairdresser came once a week. As the ward was quiet, staff often sat and watched television in the lounge area. Here, from my fieldnotes:

> *The television is on but no one but the staff are watching. Boredom descends again. Nothing happens, no one engages with the men and women. The staff are sitting in the lounge area talking to each other or watching television.*

The participants

Nora Bridges is 83 and she has a diagnosis of Alzheimer's disease. She also has a history of depression and ischaemic heart disease. Her MMSE [5] score in April 2004 was 16/30. She was admitted to the ward in October 2003 because of increasing aggression and agitation at home. Due to her failing memory, she had been assessed as requiring long-term care. She worked for many years in a city factory; a job she loved and talks of fondly. She is widowed with one son.

---

[5] MMSE: Mini-Mental State Examination (Folstein et al., 1975) measures cognitive functioning with a possible range from 0-30. A score between 10 and 19 indicates moderate dementia and a score of 9 or less indicates severe dementia. I include MMSE scores only to indicate the diagnosed level of cognitive functioning. I do not subscribe to a stage theory in considering cognitive functioning, preferring instead to look for potential rather than decline.

Nora is a sociable woman but withdraws easily when upset or bored. She communicates well but does not often initiate conversation. She is mobile and independent. She has questioned, on many occasions, her presence in the ward and expressed her desire to go home.

Edward Rankin is 73 with a diagnosis of Alzheimer's disease. He was admitted to the hospital in October 2004 with increasing cognitive decline and inability to manage at home. MMSE was not completed due to his poor verbal communication. He was married for 53 years and has one son. Following his wife's death in 2002, his health deteriorated and he was diagnosed with Alzheimer's disease. He ran a bed and breakfast with his wife and worked, at various times, as a chauffeur, a policeman and a post office clerk.

Edward had a dog, which he took great pleasure in walking. Occasionally his son brings the dog in to visit which appears to transform Edward's well-being. Edward's communication abilities are poor, comprising single words or occasionally very short sentences, but also lots of expressive miming. He is often tense and uncomfortable looking and can get angry easily.

Florence McPherson is aged 83 with a diagnosis of epilepsy and moderate dementia. Her last MMSE was carried out in October 2004 and her score was 7/30. She is from the far north of Scotland and her granddaughter told me that she feels isolated away from her Brethren culture. She was married and has two children. Her husband died in 2003 and, due to her increasing needs, she was admitted to the hospital in October 2004. She can become physically and

verbally aggressive and as a result is feared by the other patients and often avoided by staff. At times, she is heavily medicated and spends much of the day sleeping and isolated. When she is encouraged to engage and communicate her sense of humour shines through and she reminisces with pleasure.

Ward 2: the ward environment

Ward 2 is a 20-bedded ward for women. It is situated one floor up and, as it too is a locked ward, one either gains access with a staff key or rings the bell. During the study, the numbers of women in the ward varied from 16 to 18.

One enters into a corridor, which is lit with sparsely placed spotlights and wall uplighters. The walls are bare and painted a dull pale blue, the ceiling is low and grey and the floor is carpeted in dark blue. There is little natural light in the corridor and the first impression is of gloom. After a week in the ward, this seemed to be my overriding feeling of ward 2:

> *It is such a beautiful warm sunny day and I approach the ward with reluctance, knowing that I will be entering a ward where time stops.*

The first door on the right leads into a bright little sitting room with some armchairs against the walls and a little round table with four chairs around it. There is a television in the corner. The walls are bare and the wallpaper has been pulled off in areas leaving an otherwise bright room looking shabby. This room is often empty.

The second room on the right is a narrow dining room. There is a window at one end. There are four brown laminated tables placed against the walls to each side; each seating four people. There is a bright picture on one wall and a board for staff notices on the opposite wall. On one of the tables is a bowl of fruit, which the staff often offer to the women. This room is kept locked and is only accessed at mealtimes.

Then there is a large bright sitting room with armchairs around the walls. There is a dresser along the right hand wall, with a few books and videos on the shelves and a keyboard against another wall. The keyboard is always turned off. A little coffee table sits in the middle of the room and a television stands in a corner. The sitting room has big windows along the far wall, which look onto trees and, down below, a little garden. Again, the wallpaper has been pulled off in places. There are no pictures on any of the walls. This is where most of the women sit.

Along the gloomy corridor are brown locked doors; to the two well equipped bathrooms, the kitchen, the staff office, the laundry cupboard and storage rooms.

Further down the corridor, to the left is another little sitting room in which are some armchairs. There is a fish tank along one wall with big orange and black fish in it. Along another wall is a big window looking onto trees. This seems a nice little room, but it is used as a "quiet" room in which noisy women are often kept.

Right at the end of the corridor, where it widens out a little and where it is darkest, are more armchairs, a couch and a little coffee table with a vase of artificial flowers on it. There are no windows here; only a few dim uplighters, and again the walls are bare, except for a clock. Here also are locked doors to the staff room and a little visitors' sitting room, which also doubles as a staff smoking room. The staff toilets are also down here.

The corridor turns to the right and it is here that the bedrooms are. There are four bright rooms each with five beds and cupboards. Two women spend all their time in bed. Apart from the bedroom with the two women in it, the other bedroom doors are locked during the day.

The ward layout is long and rambling and the women walk its L shaped corridor or sit on their own or in non-interacting groups either in the sitting rooms or along the corridor. This gives the ward an isolating, lonely feel, as described below:

> *This is hard. It feels gloomy and stultifying and oppressive. Everyone is so scattered. There is little interaction between staff and patients (apart from functional stuff) and between the patients themselves, apart from fleeting hand gestures in passing.*

There have been plans to redecorate ward 2 and, nearly a year ago, all the pictures were removed from the walls. The plans have been shelved as other issues have taken priority in the hospital. The staff do not know when their ward will be painted and in the meantime the walls remain bare and the ward is bleak

and dim. Here, my fieldnotes illustrate the perennially dismal environment the women lived in:

> *I am sitting at the dark end of the corridor with Kate and looking along it, up towards the front door. It is so dim that I would not be able to make out whether it was day or night. Yet it is only the early afternoon and I know it is a beautiful warm sunny day outside...*

The ward staff

As in ward 1, I seldom saw the charge nurse. There was always a staff nurse on duty, accompanied by four regular care assistants, usually one or two agency staff and one or two student nurses on placement. The evening shifts had two or three fewer staff. There was also a domestic on everyday. A hairdresser came weekly. Volunteers from a nearby school visited weekly with the OT staff to chat with the women. During my time in the ward, two women required constant observation because they were at risk from falling. As this placed extra demand on the regular staff, agency staff were employed to redress the balance.

The participants

Hannah Curtis is 87. She was born in the North of Scotland and was adopted as a young girl. She was the only child in her family. She left school at the age of 15 and married young. She has a daughter and a son. She has a history of anxiety and anorexia and was admitted to the ward in July 2000 with a diagnosis of severe dementia. There is no record of a MMSE.

In her healthy days, Hannah was an artist. She also played the piano and enjoyed reading poetry. Now, her communication abilities are poor and she expresses herself through mime and facial expression. She can walk independently with a Zimmer but this is rare; being dependent on her level of confidence. She can become very anxious at times but responds well to reassurance.

Isabel McLeod is 83. She was born in England and lived there as a child before moving to Scotland as a teenager. She was married and had five children, but was widowed in her late 60s. Isabel was diagnosed with vascular dementia by CT scan in 2001. She was transferred from a nursing home to the ward in January 2005 due to increased aggression and increasing falls. No MMSE has been carried out due to "non-compliance". Isabel walks independently and communicates well when she is alert enough to do so. She has very good eyesight and will read if given the opportunity.

Brenda Gordon is 69. She was admitted to the ward in July 2003. She had a long history of memory decline and increasing agitation and was diagnosed with vascular and neurodegenerative dementia in 2002, with a MMSE score at that time of 12/30. Brenda is married and her husband visits most days. She has three daughters and one son. Brenda was a sociable woman and liked going to her local miners' club. Now her communication is limited to the occasional word. She spends most of her day walking up and down and is difficult to engage with. She requires assistance with all aspects of living.

Kate Hamilton is 85. She was admitted in December 2001 because of increasing concerns about her ability to manage at home. She had previously been diagnosed with vascular dementia and in her last MMSE (July 2001) she scored 18/30. When she was admitted, she had good verbal communication but now this is limited to one long "mmmm". She does seem to understand what is said to her and she likes to look at the paper. She spends a lot of her time in isolation but will initiate social contact when she is motivated to do so. She walks unaided. Kate worked in the WRENS during the war and later in an office in the city. She is unmarried.

Mary Mitchell is 80. She has a history of depression, anxiety and Alzheimer's disease. She was admitted to the ward in November 2004 and her MMSE score at that time was 11/30. Her husband died early in the year and she has a daughter who lives abroad. Mary has had frequent falls since her admission and now she does not walk at all, being transferred by hoist. This upsets her and adds to her sense of dependence, as in her healthy days she was a keen walker. She often expresses anxiety and her self-confidence is low.

Ward 3: the ward environment

Ward 3 is a 20-bedded locked ward for men and is situated one floor up. It is to here that men with particular challenging behaviours are admitted. Many of the men have been transferred from elsewhere due to their sexual disinhibition or aggression. There were 19 men here during my time in the ward.

One enters into a brightly lit and warmly decorated corridor. The walls are painted a pale blue and are hung with interesting paintings of familiar city street

scenes and landscapes, which I used to look at with some of the men. Here, for example from my fieldnotes:

> *We* (Bill and myself) *walk up the corridor, stopping along the way to look at the pictures on the walls. They are of the Forth road bridge; tram scenes, a busy 1950s or so street scene. I encourage him to reminisce, and other men join in as they pass us by. I now have three men standing with me, talking about the trams and the busy street scenes.*

Immediately on the left is the dining room; a narrow, cramped, functional room crowded with brown Formica tables and different types of chairs. This room remains locked outside of mealtimes. Then there is a big bright sitting room with large windows on one side looking over trees and a little garden. There are dressers on three sides of the room; furnished with ornaments and books. There are also pictures hanging on the walls. A television is bolted onto a cabinet in the corner. Armchairs line the walls, but not uniformly: they are arranged in groups. There are two couches and a coffee table in front of the television. On the floor is a richly patterned, if heavily stained, carpet.

Across the corridor are toilets and the staff office, all of which are locked. Further down the corridor, on the right is a little smoking room, which also has a television, two couches, several armchairs and a table and chairs. It too is bright and homely with pictures on the walls.

At the end of the corridor is the staff room, then the charge nurse's office. There are also armchairs down here, facing a television, and some of the men sit here instead of in the other sitting rooms.

Then, round the corner are the bedrooms, which are bright and spacious. Personal photographs or pictures hang on some of the wardrobe doors. As with wards 1 and 2, the bedroom doors remain locked during the day. Down here are also a linen cupboard, staff toilet and a clinic room.

The ward staff

A new charge nurse has recently been employed and she was regularly on duty. There was always one staff nurse on each shift, with the balance comprising care assistants and agency staff. There were usually seven staff on in the morning and six on in the evening, along with two student nurses. Cleaners and a laundry assistant also spent some time here. As there was a shortage of regular staff, particularly care assistants, there were usually several agency staff on each shift. Some of them were familiar with the ward and the men, but some of them were not. Most of the staff have no dementia-specific training, and some do not see the need for ongoing training. For example, when I asked one care assistant whether she had received any dementia training, she replied that she has had some safety training but that, as she has been here 17 years:

> *"I know all there is to know."*

The student nurses told me that they receive no support on the ward from their university tutors; they are allocated a staff nurse as mentor, and will learn from him/her.

Of the three wards, I found this one the hardest to do fieldwork in, mainly due to the damaging behaviours and attitudes of a few of the staff. It took huge amounts of willpower to remain in the ward when these staff arrived on duty:

> *The men are lovely, all of them, now that I've got to know them. And some of the staff are nice but some of them are downright scary and very intimidating… My heart sinks when I see X* (care assistant) *coming on duty, and then Y* (staff nurse)*.*

The participants

Bill Armstrong is 86. He was a miner but retired following a serious pit injury and spent the rest of his working life as a labourer. He is married and his wife visits him several times a week. Bill has a complex psychiatric history, which includes epilepsy, depression and self-harm. He was transferred to ward 3 from sheltered housing in 2003 due to increasingly erratic and sexually inappropriate behaviour. He was diagnosed with dementia in 2004 by CT scan. His MMSE in 2005 was 18/30. His communication is erratic and he seems to have little insight into his cognitive difficulties or why he has been admitted to ward 3. He is not happy to be detained here. He is mobile and independent and enjoys reminiscing and singing.

William Fairbairn is 75. He is a retired shopkeeper. He is married with two daughters and one son. One of his daughters visits regularly. He was

diagnosed with vascular dementia in 1995 (at the age of 64) following investigation for increasing difficulty with his short-term memory. He was admitted to a nursing home in 2001 but was transferred to ward 3 in 2004 following sexually inappropriate behaviour towards patients and staff. His MMSE in 2004 was 21/30. He walks with a stick and has some communication difficulties due to a previous stroke. He continues to be sexually expressive; both verbally and physically, although this has progressively lessened since his admission. William liked gardening and playing snooker and golf.

John Crombie is 79. He worked in the navy before becoming a joiner. He is widowed with two daughters. He has a history of myocardial infarction and strokes. He was diagnosed with vascular dementia by CT scan in 2004 and was admitted to the ward later in 2004 due to increasing aggression and frequent falls. His MMSE score at this time was 20/30. He is mobile but becomes breathless and exhausted quickly and requires assistance with most aspects of living. His verbal communication is poor. He can be restless and agitated, particularly in the evenings and is regularly given sedative medication to reduce his agitation.

Charlie Maxwell is 80. He is a retired miner. He is married with no children and has no living relatives. Charlie and his wife lived in social isolation and were known to be eccentric. His wife no longer visits as she is too frail. He was diagnosed with vascular dementia in 2002 and was admitted to the ward from a nursing home in 2004 with increasing aggression, paranoia, confusion and sexual disinhibition. MMSE was not completed. Charlie is a very small, frail

man with a pronounced stoop and a right-sided weakness following a previous stroke. Charlie's verbal communication is limited to short phrases and he has difficulty in being understood. He is mobile but requires assistance with most aspects of living.

Paul Johnston is 88. He has been profoundly deaf since he sustained a wartime injury. After the war, he worked as an engineer. He is single with one niece. He was diagnosed with fronto-temporal dementia by scan in 2001 following deterioration in his short-term memory and increasing aggression. He was admitted to hospital in 2002 for assessment of aggression and sexual disinhibition and admitted to ward 3 for long-term care in 2003. His MMSE score in 2001 was 19/30. All subsequent attempts to carry out MMSEs were abandoned due to communication difficulties arising from his deafness. Paul now has no verbal communication. He requires help with all aspects of living. He is passive with no displays of aggression or disinhibited behaviour. He can walk independently, but seldom does so.

Kevin Peterson is 86 and a retired hotel concierge. His wife visits almost daily. He was admitted to the hospital in 2002 for assessment of increasing aggression, disorientation and difficulties with his balance. He was subsequently admitted to ward 3 for long-term care in 2003. He has a history of transient ischaemic attacks and he continues to experience them regularly. He was diagnosed with vascular dementia by CT scan in 2002. MMSE at that time was 18/30. His condition has deteriorated rapidly and he now requires assistance with all aspects of living. His verbal communication is limited to a few

words, but he appears to understand some of what is said to him. He is no longer aggressive and his mobility is unpredictable.

Occupational therapy staff

In ward 1, Michael Tait, the art therapist facilitated the creative sessions, working alone.

In wards 2 and 3, OT staff facilitated the sessions; working in pairs. These were: Eddie O'Sullivan, Karen Lewis, Nicole Glen and Nina Jones; a trainee OT. Occasionally Michael joined them.

Gaining consent

In this section, I give a detailed account of how I sought consent from all participants, with particular emphasis on demonstrating how I gained ongoing consent from participants with dementia. This section is of value in showing how, by taking an innovative and sensitive approach, it is possible to gain consent from people with more advanced dementia.

Consent from staff

I firstly met with the OT staff to discuss my plans and to identify potential difficulties and consider solutions, for example, how would I ensure that only my participants were recorded? How would I ensure participant safety? I have discussed how I ensured these and other issues in the previous chapter. Here, from my fieldnotes is a point raised by Linda, the head OT, at one of the meetings:

> *Linda expressed the wish that we all remain honest throughout the*
>
> *research and that we communicate any concerns with each other as*

soon as we feel them. She particularly stressed that the OT staff let me know if they didn't want me to record them on a particular day, and that they should feel that it was ok to let me know. I agreed that this is very important in order to ensure their well-being, but also to make sure that feelings and concerns don't fester and damage our relationship.

These initial meetings were crucial in fostering the collaborative and supportive spirit in which video-recordings took place. Reassured of their acceptance, I gave the OTs an information sheet for reference (Appendix 13) and asked them to sign a consent form, which they did willingly (Appendix 14).

I held several meetings in the three wards with charge nurses, staff nurses and care assistants, usually at handover time so that I could catch as many staff as possible. I gave them explanatory handouts (Appendix 15), discussed the study with them and answered their questions, for example: how long would I spend in each ward; when would I start the fieldwork, would I gain patient consent? I answered each question fully; until I was fairly sure that they were comfortable with my proposed presence. I received signed consent from those who were present at each meeting (Appendix 16) and I pinned the information sheet and an introductory poster (Appendix 17) on the staff notice board both as a reminder to those with whom I had already spoken and as an introduction to those I had yet to meet.

There were many others, for example permanent staff who had not been present at the meetings, student nurses and agency staff, from whom I had not

received consent by the start of the study. I resolved this by carrying information sheets and consent forms every day and by introducing myself to new staff as soon as I could. This was particularly important during stage 2 when I required their informed consent to carry out DCM and video-recording. On most occasions, staff were interested to hear of my study and willing to sign the consent form. Here, from my fieldnotes from ward 3 is an example:

> *One new face: an agency care assistant. I explained to her what I was doing and she was very interested, asked me questions and willingly gave me her consent.*

I also experienced subtle resistance from some of the regular staff, particularly in ward 3. Here, from my fieldnotes:

> *The staff nurse is now sitting in the sitting room, so I approach him with an information sheet and a consent form. He is insistent that he has already signed a form, but I know he hasn't. I say that I'm sorry, I do not have it and would he mind signing another one. He does so. There is another new care assistant on, but she is chatting to another care assistant. I feel unable to interrupt, and even though I hover near them, they do not stop their chat. I move off, hoping I'll catch her later.*

Gaining informed consent from ward staff was an ongoing process which sometimes took up to an hour, particularly when student nurses, part-time and agency staff were concerned as they expressed interest in what I was doing and were keen to share their experiences. This was a time when I could gain insight from staffs' perspectives of work in the wards. Here, from my fieldnotes

from ward 2, is part of a conversation with a part-time staff nurse during the consent-seeking process:

She says that she feels the care is more functional than personal, but sometimes it's so busy that that is all they can manage… She looks around her at the dismal surroundings, saying that after a while she stops noticing how awful it is.

During my conversation with her, I gained an insight into how one could become desensitized to the environment in which one works.

Approval from next of kin

Following Vass et al. (2003), I initially sought approval from potential participants' next of kin. In order to avoid a charge of coercion, I asked the senior OT to give a list of regular attendees at creative sessions (of which there were 24 in the 3 wards) to the consultants of the wards. I then met with the consultants and delivered stamped envelopes containing an introduction and information sheet (Appendix 18), consent form (Appendix 19) and a stamped-addressed reply envelope, which I asked them to address and post to potential participants' next of kin.

Four weeks after handing the paperwork to the consultants, I received my first response from a next of kin, and three weeks after that I had enough responses to start in ward 1. Further replies trickled in over the next few weeks, some of which were suitable and some of which were not, for example, two potential participants did not have a diagnosis of dementia and two had died before I started on the ward.

Ethical issues in gaining consent from participants

There is debate as to whether researchers should firstly seek approval from next of kin, before seeking consent from potential participants with dementia, or whether they should seek consent from potential participants first. As a result, researchers have taken different approaches to consent; each raising different ethical issues. For example, while Small et al. (1998) and Mayhew et al. (2001) sought consent from next of kin, they make no reference to seeking consent from participants. This seems to be a serious omission in the design of these studies. Cook (2002) took an emancipatory, inclusive approach and chose to seek consent from potential participants first, before informing next of kin. However, this presumed that participants fully understood the research and its implications, and could be critiqued for failing to safeguard those who might have been less able to understand the research and its potential implications for them. In their study in a care home, Hubbard et al. (2002b) did not seek approval from next of kin of participants deemed by the manager as capable of giving informed consent, as they felt that this could erode participants' autonomy and contribute towards a process of infantalization. However, they did seek approval from next of kin of those deemed by the manager to be unable to give informed consent. This seems to contradict the researchers' desire not to erode participants' autonomy, as it has been suggested that care staff often do not recognise communicative potential of people with dementia (Killick and Allan, 2001; Sabat, 2001; Vass et al., 2003). This being so, some participants might have been erroneously deemed incapable of giving informed consent, resulting in their disempowerment. Dewing (2002) also maintained that proxy consent may disempower those who are capable of giving their own

informed consent, but she opted to incorporate consent from next of kin with that of potential participants; concluding that proxy consent should be viewed as only one part of the consent process. Similarly, Vass et al. (2003:35) stated that it was a matter of "moral principle and courtesy" to involve next of kin in the consent process, while ultimately remaining sensitive to the potentially changing cues of consent of participants. In my research, being aware of the dilemmas arising from this debate, I decided to follow the ethical stance set by Vass et al. (2003) and seek approval from next of kin first and then seek ongoing consent (Dewing, 2002) from potential participants, as I will describe below.

Consent from potential participants

I decided to work in one ward at a time and to only seek consent from potential participants when I was ready to work in each ward. I intended to use "non-cognitively challenging" methods for gaining consent (Dewing, 2002:166) and to view consent as an ongoing process rather than an *a priori* event (Hubbard et al., 2002b). This means that I tailored my requests for consent according to my understanding of the abilities of potential participants. I showed those, whose eyesight and levels of understanding allowed, an information sheet (Appendix 20) along with a verbal explanation and request that they participate. Alternatively, I verbally explained my plans to those for whom, owing to short-term memory loss or physical decline, an information sheet would have made little sense. Participants were generally happy that someone was interested enough to write about them and readily gave me their consent to spend time with them and to take notes. For example, here from my fieldnotes in ward 3:

> *I approach Charlie who is pleased to see me… He's at the end of the corridor, as usual and is sitting alone.   I ask him if I can write about his*

day. He looks at me blankly. So I ask him again. I tell him that I am writing a story and could I 'write a story about Charlie Maxwell?' At this, he lights up, smiles and says 'Aye'. I think he's pleased that I am taking an interest in him.

Subsequently, I approached participants on a daily basis with verbal reminders of whom I was and what I planned to do and with verbal requests for consent. I remained particularly alert to ongoing cues from those less able to articulate their wishes verbally and responded to their cues appropriately. For example, one day, in ward 2:

I meet Brenda coming down the corridor. She has passed by several times... She is muttering to herself and looks tense. I approach her to say hello but she waves me out of her way and then says something in a raised angry voice, which I take to mean go away. So I leave her be.

Here, Brenda made it clear that she did not want me to intrude in her life, and I took no notes about her on that day.

Along with seeking consent to observe participants and write about their days, I also sought consent for more focused methods of data-collection: DCM, video-recording and focused conversations; as discussed below.

Consent to carry out Dementia Care Mapping

During stage 2, I sought consent from each participant in turn to carry out DCM before every map. In an approach that remained consistent throughout the fieldwork, I introduced myself, showed participants the DCM recording sheets

and asked them if I could write about their day. In ward 1, my approach to Edward, before one of the maps was as follows:

> *I then ask him if I could write about his day. I ask him this a few times and include writing gestures to maximise the request sinking in. He says: 'Aye, aye', nods, raises his eyebrows and smiles. I take this to mean that he is ok with me doing DCM.*

I would approach Nora in a similar manner:

> *'Hello, Nora', 'Oh hello' she replies… I ask her if I could write about her day and she replies: 'Oh yes, so long as you don't bother me'. I reassure her that I would not be asking her to do anything. 'That's alright then'.*

In ward 2, I always showed Mary, Hannah and Isabel my papers and asked them if I could write about their day. They always agreed. One day Mary answered that, so long as she didn't have to do any work, it would be fine. Isabel always seemed pleased to help and would reply: *'Oh, aye'*. Hannah was always receptive and would often clap her hands and say: *'Oh yes'*. They seemed pleased that I took an interest in their lives.

I sometimes felt less successful with Kate and Brenda. I always approached them and said hello to them. Most times, they would respond with a smile before either walking on or disengaging. I tried to ask for their consent to write about their days, and sometimes felt that I was understood. But, in the absence of verbal communication, I was never completely sure how much they understood. On these occasions, I resolved only to map if I was sure they were

comfortable with my presence and I remained alert to visual or verbal cues signifying objection during the research process (Iacoco and Murray, 2003), such as becoming distressed. By this stage, I had interacted with them for over two weeks and they seemed generally comfortable with my presence and receptive to my interactions.

In ward 3, Bill and William clearly understood what I asked and readily gave me their consent. Some days John was sleepy or distracted and I had to repeat my question to him. Here, from my fieldnotes is a typical approach to John:

> *I approach him and ask him if I could write about his day. He says; 'I'm going away soon'. So I ask if I could write about it until he goes and he says: 'Aye!'*

Charlie usually became excited when I asked him:

> *'Aye, that's alright', he replies and then: 'We'll get you working'. He expresses pleasure at the idea that I want to write about him: his eyes fill up and he becomes emotional.*

Paul was harder to gain consent from, as I could not be certain that he understood. He did appear to read and I sometimes used to sit with him and write out sentences for him to read. On the two occasions that I sought consent to carry out DCM, I wrote out my request to him. Here, from my fieldnotes is an account of one of my approaches for consent:

> *I write on my notepad: 'Can I write about your day?' I hand him the notepad and he takes it. Then he takes the pencil and starts to trace the*

letters I have written. He spends several minutes tracing the letters slowly. He looks at me several times and smiles. I also write: 'Yes', and underneath: 'No'. He traces both words. I am not sure how much he understands, but I decide to map him, as he is not uncomfortable with my presence.

Consent to video-record creative sessions

I sought consent to video-record participants at the start of every creative session. Dewing (2002) proposed that many people with dementia are pleased to be asked to take part in research and feel that they are being viewed as capable people again. She argued that if research is to adhere to person-centred principles, then the process of gaining consent should be inclusionary. As such, information should be given in "non-cognitively threatening ways": in manageable chunks with the use of props when appropriate (Dewing, 2002:159). I followed this recommendation and encouraged participants to handle and examine the video-recorder before I sought consent to record them, as described below.

Sometimes there were up to three participants at a session and I would approach each in turn, show them the camera and ask if I could take a "moving picture" of them. Often, participants took the camera and examined it, sometimes looking at the LCD screen with interest. My fieldnotes record the approach I made to Edward, in ward 1, at the start of the first week's filming and I followed a similar routine when asking him for consent to film him on subsequent occasions:

I bring the camera over to Edward and sit beside him. I show it to him and he immediately becomes interested: 'Aye, aye' nodding and smiling. I turn it on and open the viewing panel to show him the camera panning around. He looks intently at it and smiles with interest: 'Aye, aye'. I say: 'Edward, can I take a picture of you, please?' He smiles broadly and looks directly at the camera: 'Aye, aye'.

In wards 2 and 3, I followed a similar pattern. Hannah was always interested in the camera:

She looks at the LCD screen as I pan it around the room: 'Ooh' and she makes a gesture with her hands as if looking through binoculars, smiling and nodding. I ask her could I take a moving picture of her. 'Yes, oh yes', she replies smiling.

Mary also understood and was willing to be filmed:

When Mary is settled into the room, I show her the camera. 'I know', she says. I show her the LCD screen and pan it around the room. It takes her a few seconds to focus on it, but once she does, she watches the screen. I ask her can I take a picture of her, and she said that if I liked, I could.

Isabel seemed intrigued by the camera and was also willing to be filmed:

I approach Isabel with the camera and show it to her as before. She asks: 'what is that?' and I explain to her that it is a camera and that it takes moving pictures. She is intrigued: 'Ooh'. Then I pan it round and she looks into the screen. I pan it on me and smile at her and she sees

me on the screen. I wave at her and she waves back. I ask her if I can take a moving picture of her while she does her artwork and she says: 'ooh, if you like'.

In ward 3, Bill and William were interested in the video-recorder. They understood its purpose and were happy to give consent to be filmed during the sessions. Bill would often look at the camera during filming and wave or make a funny face. John was also interested in the camera and liked to handle it. By the last day's filming, John seemed familiar with the camera. Here, from my fieldnotes is the process of gaining consent on this day:

I approach John who is now sitting at the table. I show him the camera and he says: 'I know' as soon as he sees it. He takes it from me and examines it, looking at the images appearing on the LCD screen as he moves it about. I ask him if I could film him while he is painting. At first, he is too interested in the camera to heed what I am saying, but after a minute, I ask him again and he raises his eyebrows at me and replies: 'Aye'.

Consent to engage participants in focused conversation

In this stage of the study, I sought consent from participants to show them downloaded footage of themselves taking part in a creative session and to audio-record our conversation as they told me their views of the sessions. Three participants (Isabel, Bill and William) were willing to watch the footage with me and able to give me their consent to audio-record the conversation. Here, from my fieldnotes is the process of gaining consent from Bill in ward 3:

I say hello to Bill and, when he asks me what my plans are for today, I say that I thought I might show him some of the footage and ask him for his opinion of the art sessions. I ask him if he would be willing to do this with me and he replies: 'of course, dear'.

Near the end of the focused conversation with Bill, he asked me a question, which indicated his understanding of the audio-recording technology:

…he asks whether the laptop would record him singing, I say: 'no, but the tape-recorder will'. He asks me if I would like him to sing a song and I say I would. So, he sings a song and then we replay it back and he listens and joins in.

After lunch, having already spoken about my plan with William, he approached me and:

…asks me should he go along to do the talk. I say that I'll bring the stuff here and we can do the talk at the table. I ask him if he's sure he's ok to do it; if he's tired, we could wait, but he shakes his head and says he's happy to do it now. So I get the equipment. I set it up on the table, and he looks interestedly at the laptop and begins to press the buttons. I get the tape-recorder out, show him it, and ask him if I can tape the conversation. He agrees willingly.

Summary

In this section, I have discussed the ongoing debate surrounding proxy consent and have justified my decision to seek informed approval from next of kin before seeking ongoing consent from participants. I have described how I sought

consent from staff, next of kin and participants for all three stages of the study. I have shown that, with innovation and sensitivity, it is possible to gain consent from people with advanced dementia.

In the next section, I will reflect on how I will have changed the fieldwork setting, and therefore some of the data, and on how carrying out fieldwork in the three wards had a profound effect on me as nurse, researcher and humane being.

Reflections on fieldwork

Ethnography entails social interaction in the field. Because of this, it was inevitable that my presence would have some impact on the social setting and on participants. A positivist might view this as a problem to be avoided, however a constructionist accepts that, as knowledge is co-constructed by researcher and participants, data-collection is also shared by both parties (Silverman, 2001). As such, it is important to reflect on how I also will have co-constructed the data I gathered throughout fieldwork. It is also important to reflect on how the setting impacted on me as a nurse, researcher and humane being. I will firstly use extracts from my fieldnotes to show how I will have changed the setting; taking each stage in turn, before reflecting on how the setting impacted on me; how I experienced painful ethnography and painful mapping. Finally, I will describe my response to damaging interactions that I observed in ward 3.

My impact doing ethnography

Because I spent time trying to immerse myself in participants' social worlds, it seemed impossible not to change how things were for them in the wards. Here,

from my fieldnotes in ward 1, is how I grappled with the tension between engaging with participants and observing the setting as it was for them:

> *… by engaging with them in order to get to know them, I am not getting an idea of what life is like for them. I need to try to balance getting to know them and not interfering too much with the reality of life for them, while also not giving them the feeling I am disengaging from them.*

There were times when my presence changed the experience of participants as I interacted with them with an increasing sense of sorrow for them. For example, in ward 1:

> *The man who was crying earlier is still weeping sporadically…. I go to sit with him, wondering whether, if I wasn't there would someone else be? I have a feeling not, because no one has come to check on him in all the time that he has been upset.*

Later that same day, I wrote:

> *I am finding this quite hard. Do I sit back and watch zero interaction? Should I assume that if I wasn't here someone would have come to comfort him? Maybe I shouldn't comfort him, because I am potentially interfering with what someone else would be doing. But when I see no signs of any staff interacting, comforting or acknowledging upset, do I sit back and allow it to go unresolved? I don't feel that I can. So I do what I feel is right for the person.*

My presence had another effect: the men and women started seeking me out for advice and reassurance. Again, I questioned the appropriateness of my engagement with them. Here, from my fieldnotes from ward 1:

> *I am noticing that they are seeking me out for reassurance, I've heard the women saying: 'she's nice'. Is my presence interfering with the setting too much? But then again, none of the staff seem to take much interest in the concerns of their patients. If participants seek me out, I must respond, even if it does change the research setting…*(this) *is symptomatic of a particular type of setting: one in which their needs are generally ignored.*

By engaging with participants, by intervening and comforting them, my role as a nurse took precedence over my role as researcher and I undoubtedly changed their experiences in the wards. By documenting and justifying such interventions, I have tried to maintain a balanced and accurate picture of each ward, while maintaining my own humanity.

My presence had one positive effect on one of the student nurses in ward 1. It was lunchtime and, as always, I sat at a table with the men and women:

> *I notice that the student nurse joins another table and the mood there livens up. Laughter comes from his table, I catch his eye and we smile.*

While I appeared to have had a positive impact on participants and non-participants, I seemed to have had a negative impact on some of the staff, who

were rude and indifferent at times. Here, from my fieldnotes is a typical observation of one of the care assistants in ward 3:

> *I have been getting lots of glares from X. She makes me uneasy. Maybe I make her uneasy too.*

While I tried to remain inconspicuous, on reflection, I did stand out sharply; particularly in my friendly, engaging attitude towards participants, non-participants, student nurses and anyone else who would engage with me. Although I may have altered the setting somewhat, it was not enough to prevent some of the damaging interactions that I observed, particularly in ward 3. I often wondered what happened when I wasn't there.

My impact during Dementia Care Mapping

The most difficult part of mapping was having to distance myself from participants, and realising that, emotionally, I couldn't. This method, in contrast to the spirit of ethnography, requires that the researcher detach herself, in order to map with objectivity. Once I started mapping, I quickly realised how isolated participants' lives could be, how little sustained interaction they received and how difficult it was to detach myself from them. Many times participants turned to me, looking for interaction or reassurance and I would always stop mapping and engage with them for a short time. At other times, I intervened to prevent possible harm to participants. These timeframes were never counted as data.

Here, from my fieldnotes in ward 2, is an account of how I intervened to alleviate Hannah's increasing distress during one map:

There is a care assistant and a staff nurse in the sitting room but they don't seem to notice… I abandon the map. I go to talk to Hannah who is now distressed: whimpering, looking very anxious; rocking back and forth. I put my arms around her and try to sooth her. I find the book of photos and bring it over to her and we spend an enjoyable 10 minutes looking at it and admiring the photos. After 10 minutes, I return to complete the map and leave Hannah contentedly looking through the book by herself. The final 20 minutes of Hannah's map will not count as data.

Here from my DCM notes is another account in which I intervened to prevent a possible accident. After lunch one day, Kate was walking in the sitting room. She approached a woman:

She takes her wrists and tries to pull her from her chair. This woman is volatile and likely to hit out. Two care assistants are in the room but are busy feeding people and do not notice. I am concerned for Kate's safety and after watching her attempts to pull the woman from the chair for about 10 seconds I intervene and extricate her from Kate's grasp.

In ward 3, all of the men, apart from Paul and Kevin who were unable to move without help, approached me many times during each map and I could not ignore their needs for social contact, nor could I ignore times when they needed help. One day, while mapping, I wrote about Charlie in my DCM notes:

He goes into the little sitting room and spends the next 20 minutes in isolation, opening and closing the door… I notice that the door is closed

and the handle is moving up and down. I assume that Charlie has locked

himself in. I open the door with my key and he's there... Charlie is nearly

crying, he's relieved to see me. This timeframe is not counted. He sits

down and wants me to sit with him which I do and I talk gently with him…

not counted.

Throughout stage 2, I was aware of a constant tension between intervening and interfering. When does intervening become interfering? At what stage should I intervene? I justify my interventions on two grounds:

- Having spent two weeks in each ward, participants now knew me quite well. I could not ignore their needs for social contact once I started mapping, for to do so in order to get "accurate" data might have appeared rude to them and damaged their personhoods further.

- On occasions, my ethical stance took precedence and there was no question that I would interact. When it came to interrupting a map to comfort Hannah or Charlie, or to safe-guard Kate or Brenda there was no dilemma: their well-being always came before data-collection.

The fact that I had to intervene is a sufficient indicator of the generally poor state of affairs in the wards. However, this also meant that some participants' WIB values were probably misleadingly higher because I had prevented their well-being from deteriorating further. This was particularly the case for Hannah, Mary and Charlie, and highlights the need for detailed documentation of interventions in order to account for possible over-rating of WIB values.

My impact during filming

On the first day of filming in ward 1, my presence meant that the video-footage was unusable. I had asked Edward for permission to film him and he had agreed. When I set up the camera, Michael had moved on to someone else. I wondered whether I should stay with him or leave him, but decided that if I left him to it, he would probably disengage and that would be a wasted creative opportunity for him and a wasted research opportunity for me. I stayed and encouraged him to paint. Later, I realised that by staying with him I had altered the setting. By facilitating an opportunity that he might not have had, had I not been there, I had not reflected the reality as it might have been for him. I have not included the data from this session in the study.

Subsequently, I was careful not to interfere during creative sessions. However, while I tried to remain inconspicuous, my presence was sometimes noticed by participants who waved or smiled at me if they caught my eye. Rather than becoming anxious about having such an impact, I interpreted participants' occasional engagement with me as both a sign that they were comfortable with my presence and a sign of their continued consent to being filmed.

Impact on me: painful ethnography

During my time in the wards, I experienced the boredom, sorrow, frustration, distress and fear that the men and women regularly felt. My notes from ward 1 are typical of my fieldwork experience:

> *The routine is numbing, the lack of warmth heart-breaking.*

I cannot get over the lack of interaction here. The ward is so quiet, yet all they (the staff) *do is sit and watch TV, when they are not giving out food or drugs. Only the student nurses and one of the care assistants attempt to interact in a meaningful way.*

Time is passing so slowly. I find myself walking around, looking for something to do, someone to chat to…

In ward 2, I experienced the numbness of inertia and the tension of pent up restlessness:

At 4.00, feeling claustrophobic and tight chested, I head out for coffee. Three quarters of an hour later, I return and nothing has changed. The sleeping women are still sleeping, those that are walking up and down are still doing so, the big sitting room is still devoid of staff….

But I also experienced guilt that I could leave at any time:

I feel odd, opening the door and walking through it, a free woman.

During my time in ward 3, the abusive, oppressive nature of the ward and the intimidatory attitude of some of the staff made me very uncomfortable. As soon as particular staff came on duty, my heart would sink and I would have to steel myself to stay on the ward. After receiving sharp admonishments from particular care assistants, I found I was constantly trying to avoid potential conflict and I became angry with myself when I realised that my fear of conflict influenced

how I interacted with the men. One day, following an incident when a care assistant shouted at us when William kissed me good-bye:

William calls me over, stretches out and takes my hand and bends his head down to kiss it, but I say, knowing that X is on: 'William, you and I got a row last week, I don't want you to get another one'. He understands, but is put out and waves me away and I immediately feel that I have let him down by denying him what really is just normal social contact… The power of certain staff has got to me and they now influence how I respond to William.

At times, I felt that their intimidation had rendered me impotent and I became angry at my weakness. One day, all the staff were on their break and I was alone in the sitting room:

15.00 - I look around to make sure that every one is all right and I spot one of the men lying on the floor. I go to check on him and see that he is sleeping… I go to look for someone, but they are all on their break… the break goes on and on. I catch a care assistant at about 15.30, and I tell her that the man is lying on the floor sleeping. She replies that they know he is on the floor and that they are leaving him there for now, because "at least he's not getting up to anything"… After nearly 1½ hours on the floor, the staff finally attend to him… I want to cry: with sorrow, disbelief, despair and anger at myself for being cowardly and for not insisting that the staff lift him off the floor.

One evening, near the end of my time in ward 3, I avoided going to say goodbye to Paul and Kevin because eight staff were sitting together in the sitting room:

> *I feel uncomfortable now; with all the staff sitting together, knowing that they know I'm here and wondering what they are feeling or thinking, and what they'll say when I go. So I leave the sitting room… I have reached my limit, I am uncomfortable and don't want to spend any more time here. I decide to go home and feel an immediate sense of relief, but also sorrow for the men I am leaving behind.*

Taking an ethnographic approach in ward 3 challenged me to my limit. Shortly after the entry noted above, I decided to cut short the study; leaving before I could explore whether Charlie and Paul might have taken part in creative sessions.

Impact on me: painful mapping

On reflection, I was not prepared for the cumulative impact of empathising with the men and women in these wards. I carried with me the sorrows and frustrations of ward 1, the dim oppression of ward 2 and the harshness of ward 3 without being able to let go. As I got to know my participants; gaining a feel for how things were for them, my empathy grew to the extent that it sometimes became painful to observe their isolation or distress. During stage 1, by trying to make their days more bearable I felt less distressed for them, but the process of mapping changed all that. As a mapper, I had to try to disengage, but I quickly found that I couldn't. I felt Edward's frustration, Nora's irritability, Florence's indignation, Hannah's distress, Charlie's isolation; I felt distressed and lonely for

them. I saw what an impoverished social life they led, now that I was no longer available to engage with them and I felt, with an increasing sense of impotence, the harshness of ward 3.

Unable to watch participants' distress and unwilling to ignore them when they reached out to me during mapping or were in danger, I intervened to comfort or engage with them, as described previously. By taking this approach, I was able to manage my sorrow and to continue mapping with my humanity intact.

Summary

In this section, I have shown that fieldwork is not always a comfortable experience for the researcher; she/he will have to grapple with emotional and practical difficulties and dilemmas, negotiate the balance between intervening and interfering and will have to make decisions that reflect her/his own enduring humanity. Yet, exposure to and insights gained from such emotional danger (Lee-Treweek, 2000) have added immeasurable depth to my understanding of participants' everyday social worlds in institutional long-term care, as I will describe in the next two chapters.

Ethical issues arising during research

In the previous chapter, I discussed ethical issues in carrying out DCM and video-recording, in terms of consent, harm to participants, confidentiality and use of data. In this section, I will focus on my response to damaging staff interactions.

Response to damaging staff interactions

I decided that I would have to report the damaging and abusive behaviours that I saw in ward 3 to the charge nurse. When I did, she asked me for the names of the staff who were involved, so that she could discuss my concerns with them. Shortly afterwards, she went off on long-term sick leave and I did not find out whether she had discussed the issues with the staff. I then decided to inform the hospital manager, because damaging interactions were continuing on a daily basis. She told me that things were changing and that she would increase her presence in the ward now that the charge nurse was off sick. Although relieved that I had acted in accordance with DCM and ethical principles, I was unconvinced that she really appreciated the severity of my claims and concerned that practice would not improve. Yet, as a visiting researcher, with little control, I felt I had done all I could for the time being.

Conclusion

In this chapter, I have described the three wards and indicated their staffing levels. I have used pseudonyms to introduce the art therapist and OT staff and pseudonyms and biographical information to introduce the 14 participants.

I have discussed the debate regarding proxy consent from next of kin and described how I opted to seek informed approval from next of kin before seeking ongoing consent from participants. I have described, in detail, the process of seeking consent from participants and suggested that, with innovation and sensitivity, it is possible to gain ongoing consent from people with more advanced dementia.

I have also described how fieldwork was not always an emotionally or psychologically comfortable experience. It required constant reflection, decision-making and, increasingly, steely willpower.

In the following two chapters, I will discuss my findings; illustrating the analysis with fieldnotes, DCM data and descriptions of and quotes from participants.

Chapter 6: Interactions and participant well-being

Introduction

This thesis; its theoretical foundations (in the form of symbolic interactionism and social constructionism), its methods (in the form of non-participant observation, DCM and video-recording creative sessions) and its analyses (seeking elements of malignant social psychology, positive person work and expressions of Self) focused on types of interactions that participants received in the wards and during creative sessions. For these reasons, it follows that my findings will also focus on interactions. In this chapter, I focus on interactions and participant well and ill-being, and in the following chapter, I focus on interactions and expressions of Self.

Interaction occurs when two or more people engage in an activity together over a period of time. This could include a brief exchange in the street, a hug between friends or an extended period of communication. From a symbolic interactionist perspective, the basis of interaction is shared meaning and understanding (Blumer, 1969), while from a social constructionist perspective, interaction involves a reciprocal process of giving and receiving either confirmation or disconfirmation of one's existence in the world (Laing, 1961). In dementia care, interactions occurring within relationships; whether formal or informal, have the potential to enhance or reduce well-being and this is particularly so as cognitive decline increases (Kitwood, 1997).

In this chapter, using Kitwood's (1997) elements of malignant social psychology and positive person work as identifiers of interaction types, I describe the types of interaction that I observed between staff and participants in the three wards and during creative sessions. I also describe participants' levels of well/ill-being in the wards and during creative sessions, in relation to the different types of interaction they experienced. Throughout this chapter, I support my findings with fieldnotes, DCM notes and quotes from conversations with participants.

Interactions in ward settings

I observed two broad ways in which ward staff interacted with participants: positive and negative. Positive interactions resembled Kitwood's (1997) positive person work and, while most often brief and task-related usually briefly raised participants' well-being. Negative interactions followed malignant social psychology and ranged in severity often resulting in participant ill-being.

Positive staff interactions

Of Kitwood's (1997) 10 elements of positive person work, I observed regular *recognition* in all the wards, occasional *validation* and *celebration* and very occasional *relaxation*, although these last three occurred more in some wards than others. As most positive interactions mainly occurred alongside the performance of tasks, they were often briefer and less intense than advocated by Kitwood (1997). In wards 1 and 2, staff sometimes provided *occupation* for the men and women. While Kitwood does not include occupation as an element of positive person work, he does include it as one of the five main psychological needs of people with dementia; the other four being attachment, comfort,

identity and inclusion. Provision of occupation by ward staff increased participants' well-being, so will be included as positive staff interaction.

Recognition

Kitwood (1997:90) defines *recognition* as occurring when a person with dementia is acknowledged as a person, known by name and affirmed in his/her own uniqueness. Staff often addressed the men and women by name, for example, in ward 2:

> *A care assistant approaches Isabel, addresses her by name and invites her to come for lunch. She smiles kindly at Isabel and they walk towards the dining room together.*

And, in ward 3:

> *A care assistant comes in and greets William warmly: 'Hello Will, how are you doing?'*

Even though recognition usually occurred in conjunction with tasks, it still had the potential to increase well-being. Here, from my fieldnotes in ward 2:

> *A care assistant helps Isabel to eat. Initially she stands over her but then she squats down beside her and engages with her. The care assistant smiles kindly at Isabel and Isabel smiles back. Her well-being increases.*

Occasionally, staff affirmed the uniqueness of the men and women. Here from my DCM notes from ward 1, is a rare animated encounter between Edward and a staff member whose recognition gave Edward great pleasure:

The staff nurse has a job to do and tells him she will be back. He stands and waits for her. When she comes back…she gives him a great welcome and he returns the greeting: 'Aye, aye'. When she leaves him, he says: 'see you later'. His well-being rises to +3.0.

Kate and Brenda in ward 2 and Charlie, Paul and Kevin in ward 3 experienced little interaction and received scant recognition from ward staff. They remained most isolated. For example, here from the Individual Care Summary of Brenda's first map:

She spent over ½ of the map walking, mostly in isolation and this meant that she had little opportunity to interact with others. While the care she received was kind but functional, there was little attempt at sustained engagement.

Validation

Kitwood (1997:91) defines *validation* as acknowledging the reality of a person's emotions and feelings, and giving a response on the feeling level. Validation occurred occasionally in all three wards, although it usually accompanied a task and it more often acknowledged feeling states rather than empathising with emotions. Here, from ward 1, when a staff nurse spotted Florence shivering, she:

… pulls the shawl up over her head and tucks it around her, cosily.

Once in ward 2, a care assistant validated Isabel's love of fruit and, by offering her an orange, she increased Isabel's well-being:

> *When Isabel has finished her desert, a care assistant offers her an orange, which Isabel accepts with pleasure; she loves fruit.*

In ward 3, there was little warm engagement and I seldom saw validation. However, on this rare occasion, a care assistant seemed to empathise with William's excitement about going out with Eddie (OT) and he responded warmly:

> *William is still waiting at the front door and the care assistant explains that he'll be going out later: 'you can get your dancing shoes on then!' he laughs and William chuckles.*

By acknowledging William's excitement at going out and sharing the moment with him, the care assistant raised William's well-being.

Celebration

Here, the mood is expansive and convivial; life is experienced as joyful, caregiver and cared-for are taken up in a similar celebratory mood. In ward 1, one care assistant, H had a warm relationship with Edward and often when she was on duty she and Edward would fool around together. One day, I observed in my fieldnotes that:

> *The staff are getting some patients ready to go for a walk and Edward is one of them. H and he fool around, making monster faces and gestures at each other and laughing.*

On another occasion, Edward and a nurse that he liked also had a celebratory interaction. He had been sitting looking bored and restless:

…he gets up and walks into the office. He gets a lovely welcome from the nurse, he makes a funny face, picks up the nurse's hand and kisses it and then kisses her up the arm. She laughs: 'thank you, Edward'. Edward pats her on the back. He starts to fool around, picks up a walking stick and pretends to be an old man; making funny faces. He then picks up a pair of glasses, puts them on and makes another funny face. There is lots of laughter coming from the office.

Here, the spontaneous, reciprocal nature of the interaction turned a dull afternoon into one of laughter and joy for a short while.

I saw no instances of celebration between staff and participants in wards 2 and 3.

Relaxation

Of all the forms of interaction, *relaxation* has the lowest level of intensity and the slowest pace. Relaxation occurs when the caregiver stops active work and rests with the person with dementia (Kitwood, 1997). Of the four instances of relaxation I observed in the wards, only one met Kitwood's description, and this involved a student nurse and a non-participant. The other three, having some element of relaxation to them, were the closest to Kitwood's description that I saw in the wards. Here, from ward 2, is one such occasion and although I could not hear the full conversation, I could see its impact on Hannah's well-being:

A lovely interaction takes place between Hannah and the staff nurse. The nurse sits with her and Hannah says: 'beautiful, beautiful, thank you'.

Here, from my DCM notes in ward 3, is a rare moment of tranquillity in which John seemed to enjoy the close attention:

> *John sits in the chair and soon afterwards, the student nurse comes and chats with him. They spend a few minutes in quiet close engagement.*

However, in the time and task-oriented environment of the wards, staff did not appear to understand that sitting with their patients was an important part of their work. This was brought home to me one day, in ward 1. Here, from my fieldnotes:

> *I am at the far end of the corridor chatting to someone and a student nurse stops to join in. After about 20 seconds, she says 'better go now and do some work. I'll get a row for chatting', and away she goes.*

Occupation

Very occasionally, interactions between ward staff and participants had an occupational element. Kitwood's (1997:83) definition of occupation is "to be involved in the process of life in a way that is personally significant and which draws on a person's abilities and powers". The need for occupation still exists in people with dementia and is seen when they want to help, to be involved in activities or to carry out familiar tasks. I include this as part of positive interaction because, in the numbing routine of everyday ward life, when staff did provide occupation, participants reacted with enthusiasm.

One afternoon, in ward 1, Nora and another woman were sitting in the lounge area listening to the staff talking together. Suddenly a care assistant asked them if they would like to help her with the laundry:

They agree and join her at the trolley, which is piled high with sheets and towels. They go to the laundry cupboard to help stack the shelves. Then they leave the ward with a folded cardboard box each; for uplift. They return, eyes shining.

On this occasion, the boredom of everyday ward life was alleviated and the women experienced a sense of purpose for a time; raising their well-being.

On another occasion, the staff nurse that Edward liked was heading for the dining room with the drug trolley. She asked Edward to come for lunch, but he refused:

Then she asks him to help her to push the trolley up to the dining room. Up he jumps and, making his funny face he starts to push the trolley towards the dining room. He pushes it all the way up and positions it where the nurse indicates. 'There, there' he says.

On this occasion, the nurse skilfully worked with Edward's need for occupation and turned a potentially conflictive situation into a collaborative one.

In ward 2, I observed one occasion in which a care assistant started a ball game with some of the women. This was a half-hearted attempt to engage the women in activity so I coded it as *occupation* rather than *play*. Play being more of an exercise in spontaneity and self-expression is not directed towards a goal, whereas occupation is. While the women enjoyed this activity, the care assistant engaged with minimal enthusiasm:

> *A care assistant starts a ball game and throws a ball to the women in*
> *turn. She throws the ball to Hannah a few times and Hannah responds*
> *with pleasure, throwing the ball back and chuckling. But the game only*
> *lasts about 10 minutes…*

In ward 3, the regular staff provided no occupation. They considered this to be the role of others, for example, student nurses or OT staff. From my fieldnotes in ward 3 is an illustrative account of an argument over who will accompany Eddie on his weekly evening trip to the hospital social club with some of the men:

> *Eddie arrives to remind the staff that he intends to take some of the men*
> *to the social club this evening for the folk session. He would like some*
> *staff to accompany him... The staff are arguing about who will go. 'It's not*
> *in my job description' says one care assistant.*

This extract is representative of the ward staffs' apparent unwillingness to engage in anything other than task-related interaction.

Positive interaction from others

It quickly became clear that those who interacted most often and most positively with the men and women in all three wards were not the regular staff, but visitors, student nurses, some of the agency staff, the minister who visited weekly, a weekly theatre group and the OT staff.

In ward 1, a group of actors visited weekly and improvised with some of the men and women using song and slapstick humour. Those who joined in usually had a great time. Here, from my fieldnotes is my first encounter with this group:

> *I hear clapping and voices coming from the small sitting room further down the corridor. A man and two women are dressed in funny clothes. Five people are there, including Nora and the session is in full swing. Nora watches quietly, but slowly becomes more responsive; her eyes brighten and she starts to smile… she playfully swats the man's bowler hat.*

However, some of the ward staff seemed to resent their presence. For example, the staff nurse:

> *… is not happy; muttering crossly at the presence of the group., 'They're not children' and 'Children's stuff'...*

These comments could indicate the staff nurse's concern to ensure that his patients were not infantilized, yet he did not attend the group to monitor for infantilization or to observe the humour, improvisation and enjoyment that his patients experienced. Rather, his comments seemed to reflect an unwillingness or inability to recognise the potential for spontaneity and humour in his patients.

One day, also in ward 1, a woman with a dog called Millie came to visit. Here is what happened:

> *Edward instantly lights up and becomes more animated than I have seen him. He bends down to pat her, follows her up the corridor and tries to*

talk to her. Several men and women flock to Millie, lots of 'oohs' and 'ahhs'. I wonder where the staff are? They are either watching TV or in the office.

While the student nurses were on their placement, they sometimes played dominoes or cards with the men in ward 3; fulfilling their needs for occupation for a short time:

The student nurse… is in the sitting room at the little table playing dominoes with three men.

Although most of the agency staff interacted very little with the men, there were four, on four different occasions, whose presence had a positive impact on the men in ward 3. On one occasion:

Bill is in the sitting room engaged in an animated conversation with one of the agency staff. They talk for 25 minutes about Gaelic and where they are both from...

On this occasion, Bill experienced an extended period of well-being as he engaged in interaction that featured elements of recognition and celebration.

In ward 3, the minister or Eddie (OT), most often engaged with the men. Eddie regularly brought musical instruments, CDs or interesting books to the ward and spent time singing and chatting with some of the men. The minister visited weekly and always tried to spend time with the men, individually or in groups.

Here, from my fieldnotes is an account of one of her visits in which celebration featured:

> *She is in the little sitting room with Bill and William and they are chatting and reminiscing. The reminiscing turns to singing and Bill's voice booms around the ward.*

Summary

In this section, I have described elements of positive interaction that I observed in the wards, mainly following Kitwood's (1997:90-91) positive person work. Ward staff most often recognised their patients; they called them by name and occasionally engaged in deeper recognition of their uniqueness. They sometimes validated their feeling states, and very occasionally engaged in celebration, relaxation and occupation. While most of these interactions accompanied tasks and were therefore brief, they still raised participants' well-being, although it often seemed that this was a consequence of interaction rather than the purpose of it. Many positive interactions occurred with others: OT staff, the minister, visitors, the theatre group, agency staff and student nurses and these interactions seemed to be more purposeful in increasing participant well-being. Some participants, notably Kate, Brenda, Charlie, Paul and Kevin seldom experienced positive interaction from anyone and they seldom experienced well-being as described later.

Negative staff interactions

While I observed some positive interactions in the wards, many more were limited in their potential for facilitating or maintaining participants' well-being. In all three wards, I observed a range of negative interactions: *no interaction*,

limited interactions and *damaging interactions*. In ward 3, I observed *abusive behaviour*. All of these interactions contained elements of malignant social psychology in varying degrees of severity, and I will discuss each in turn.

No interaction

Ward 1 was quiet when I was there, with only 11 of the 20 beds occupied. There was little for the staff to do as most of the men and women were mobile and could carry out basic tasks of daily living independently, for example going to the toilet or eating. When their work was done, the staff mostly sat in the lounge area, often together, reading the paper, watching TV or talking among themselves. My fieldnotes are scattered with observations like:

> *Nothing is happening. People are walking up and down, up and down looking for something to do. The staff are sitting watching TV and talking to each other. No one is talking with the men or women or noticing their restlessness.*

After a week in ward 2, I realised that, here also, staff made little attempt to engage with the women on completion of tasks. Most often when their practical work was done, the staff would sit in the sitting room and chat to each other and the women would sleep, sit alone or walk up and down. This is what I wrote at the beginning of week 2:

> *So far, I have seen no attempt by staff to do any activity with the women; no reminiscing, no playing music, no looking at books or magazines, no singing, no playing games…*

My fieldnotes from ward 3 contain many similar observations:

190

> *It is busy with staff in the sitting room: four of them are sitting watching*
>
> *television. Nothing is happening for the men.*

In these extracts, the main element of malignant social psychology is that of *withholding*; refusing to give asked-for attention or to meet an evident need. Here, participants' needs for occupation and interaction were unmet, often resulting in restlessness and ill-being.

I often wondered whether staff chose to ignore their patients' needs or whether they genuinely did not notice. However, there were occasions when it was clear that a staff member chose to ignore their needs. Here, from my fieldnotes is one example from ward 1. I was doing a jigsaw with one of the women. A staff nurse had been sitting close by reading a paper for nearly an hour:

> *A man approaches us at the jigsaw table. He says he needs 'the loo'.*
>
> *The woman beside me stands up to try to help him; both head towards*
>
> *the toilet. Another staff member spots them and takes over. The woman*
>
> *returns to her jigsaw; breathless. The nurse must have seen the male*
>
> *patient's request for the toilet and the female patient's breathless attempt*
>
> *to take him there. He is sitting opposite us, but he does not respond.*

I observed a particularly poignant example of *withholding*, in ward 2, during Hannah's final map in which staff ignored her nearly constant distress. Here is what I wrote after the day's map in which I frequently intervened to alleviate her distress, which had escalated following a serious fall a few days previously:

Poor Hannah looked so frail and was so distressed… The saddest thing
is that none of the staff took any notice of her, apart from the staff nurse
who asked if she was 'alright in there' but walked away before Hannah
could engage with her.

Here, along with *withholding*, is an example of *outpacing*; when the nurse failed
to wait for Hannah's response.

Limited interactions

Many of the interactions between staff and their patients were limited in their
potential to nurture and sustain well-being. This was because they were brief
and functional; being time and task-oriented and minimal.

Time and task-oriented approach

In all three wards, participants received time and task-oriented care: care was
delivered according to a rigid time schedule and in order to achieve tasks, such
as taking patients to the toilet and ensuring they were fed.

Here, from my DCM notes, is an account of the time and task-oriented nature of
care that Nora received in ward 1:

Although the ward was quiet, few staff members engaged with her for
anything other than brief episodes of functional care.

From my fieldnotes in ward 2:

Medication time. The staff nurse is firm and functional and dispenses
medication without any extra interaction.

There are many entries in my fieldnotes documenting the time and task-oriented approach in ward 3:

> *The staff have spent a lot of time sitting in the sitting room chatting to each other and watching television. This afternoon, after taking the men to the toilet at 15.45, they sat chatting amongst themselves until 17.00; until it was time to get the men along to the dining room for their tea.*

Minimal interactions

In all three wards, time and task-oriented care resulted in minimal interactions. In ward 1, I observed how staff worked in ways that were separating:

> *When lunch is served, the staff stand at the food trolley, watching and chatting to themselves and only interacting to intervene.*

My first map in ward 2 brought the minimal nature of interactions home to me most clearly:

> *Only when I am not engaging with the women do I realise how little other sustained and meaningful interaction they receive.*

Brenda was the most isolated of the participants in ward 2 and received only brief, functional interaction from the staff. Here, from the summary of her fifth map, is a representative account of how she usually spent her days:

> *This has been a lonely day for Brenda. She has spent 57% of her time walking alone … There were a few staff interactions but they were functional or very brief.*

I also observed how time and task-oriented care was carried out as quickly as possible; further reinforcing the minimal nature of interactions. This was most evident in ward 3:

Tea seems rushed. Charlie is eating slowly but a care assistant comes and feeds him; big spoonfuls of food...Soon tea is over and the men are brought out again.

The most telling indication that tasks were done as quickly as possible was when staff pulled the men along with them; to and from the toilet or the dining room *(outpacing)*. My fieldnotes are full of observations such as:

Tea time. A care assistant comes and calls out to Charlie to come for tea. She takes him by the hand and pulls him down the corridor.

And:

Several minutes later, a student nurse comes to take John to the dining room. She pulls him by both hands down the corridor. John staggers because the student is going too fast for him.

Paul and Kevin, the most passive of the participants in ward 3, were also the most isolated; receiving a bare minimum of interaction. Here, from my fieldnotes is what their days were like:

They sit where they have been put, they occasionally look around them, Paul rocks and bends down to lick the table or sits with his long tongue stretching down to his chin. Kevin blinks slowly and sits. They do not

initiate interaction. They sleep. The only interaction they receive from the

staff is when they are being fed or taken to the toilet.

Damaging interactions

In all three wards, I observed and documented all 17 elements of malignant social psychology with varying degrees of frequency and severity. In ward 1, Florence often experienced violation to her personhood and during these times, she could become distressed and aggressive. On this occasion:

Florence, who has become aggressive hits out at a man, the staff jump in

to remove her from him, she is shouting and trying to hit out. Two staff

take her, one by each arm and hustle her to the other end of the corridor.

We don't see her for the next five minutes. When she returns, she is

flushed, breathless, indignant and still volatile.

Here, Florence experienced *banishment*; she was physically removed from the main ward area and she experienced *intimidation* through the staffs' use of force in their interaction with her.

There were many instances when staff engaged in *imposition*: they forced participants to do something, overrode desire or denied them choice. One day, in ward 2, Isabel did not want to go to the dining room for her lunch. The staff member:

…pulls her from her chair and pulls her, unwillingly, into the dining room.

She then pushes her into a chair.

Another time:

> *Kate is not keen to sit at the table; she stands back up when the student nurse sits her down. Kate has stood up again and starts to walk off. This time, the student pulls the chair around so that it is behind her and he forces her to sit by pressing down on her hips. Once Kate is seated, he pushes the chair close to the table so that Kate cannot stand up again.*

In this example, as well as *imposition*, the student nurse engaged in *objectification*: treating Kate as if she were a lump of dead matter - to be pushed and pulled without regard to the fact that she was a sentient being.

A very frequent type of damaging behaviour occurred in wards 2 and 3 and most often occurred when staff had taken participants to the toilet or from the dining room. Instead of returning with them to their chairs, they would leave them, either in the corridor or at the door of the sitting room. On these occasions, staff not only caused *disruption* by suddenly intruding on participants' frames of reference, and *outpaced* and *disempowered* participants by pulling them along instead of allowing them to walk at their own paces, they also *objectified* them by not returning with them to their chairs. In ward 2, Kate experienced this every day:

> *A care assistant comes to take Kate to the toilet. She approaches Kate brusquely and pulls her towards the toilet. She leaves Kate in the corridor after returning from the toilet.*

In ward 3, Charlie, Paul, and John also experienced this daily:

The staff come and take Charlie to the toilet but walk with him far too quickly... When they return a few minutes later, they leave him standing on his own and he remains there looking lost.

And:

The staff nurse returns with Paul and leaves him in the middle of the sitting room. Paul stands; not even looking around, just standing.

These, apparently unintentional, ways of interacting with participants seemed to reflect staffs' lack of awareness of their patients' sentience and selfhoods.

Abusive behaviours

The most damaging behaviours occurred in ward 3, when staff were verbally or physically aggressive to the men or treated them in dehumanising ways. These behaviours often caused ill-being. One afternoon, Charlie walked into a bathroom where staff were working with another man. Here is what happened:

Two care assistants are in the bathroom with a man who is shouting and cursing. Charlie walks into the bathroom but about four seconds later, he is roughly pushed back out again. Charlie walks away, he looks pale, he is dribbling and disengaged.

Here, he experienced *intimidation*; in which the use of threats or physical power causes fear, along with *banishment* and *objectification*.

One care assistant was often verbally aggressive, particularly towards William. On this occasion, as he leaned over to kiss me goodbye on the cheek, she shouted from across the sitting room:

> *'No, that's not on'. I reply that he is only kissing me goodbye on the cheek. She replies loudly: 'That's what he's in for'.*

Here, William experienced *labelling*; the care assistant used his pattern of behaviour as the main basis for interacting with him, and *stigmatization*; she treated him as if he were an outcast. In symbolic interactionist terms, she negatively positioned him as deviant. My fieldnotes following this incident, while brief, convey my sense of controlled rage; indicating that her aggression towards William affected my well-being also:

> *I am so angry with her that I fear what I might say to her, so I refrain and walk away.*

Another time, after tea, when William was waiting to go out with Eddie, the same care assistant:

> *… tells him to go in for his tea. He says something which I cannot hear, but I hear her response: 'You don't eat your tea, you don't go'. William meekly goes in, sits down and waits.*

Here, William experienced *infantilization*; being treated in a patronizing manner and *invalidation*; failure to acknowledge his subjective reality – in this case, his excitement at going out. He also experienced *intimidation* and *imposition*. His excitement at going out rapidly dissipated.

In wards 2 and 3, some of the more mobile women and men were often placed on reclining chairs to prevent them from walking around and they were also controlled by medication; extreme forms of *imposition*. One day, in ward 3, as I was sitting with Paul, the staff nurse came over to look at a man sleeping in a reclining chair nearby:

> *He tells me is a bit concerned; he sedated him after lunch because he was getting worked up, trying to take his shirt off and getting aggressive. He says that the medication seems to have hit him harder than he had anticipated. 'But he's still alive', he remarks as he walks away.*

In this extract, along with *imposition*, there is *banishment*, *objectification* and possibly *invalidation* as the nurse had not tried to understand the reasons for the man's restless behaviour.

Here from my fieldnotes is an incident, in which *imposition* and *intimidation* featured strongly:

> *There is a commotion from the dining room; crashing and then staff shouting. I can't see what is happening. A minute or so later there is more shouting, and the staff nurse and a male care assistant appear with a man, hustling him into the sitting room. He is angry and shouting and trying to hit out, but the staff are bigger and stronger than he is, and shout louder. The staff bundle him into a chair and shout at him, he hits out but is restrained. I see fear in his face.*

I saw other occasions of abusive and dehumanising behaviour in ward 3, which I reported to the charge nurse and the hospital manager, as discussed in the previous chapter.

Summary

In this section, I have described a range of negative staff interactions that I observed in the wards. I have described *no interactions* in which staff generally ignored the needs of participants and *limited interactions*, which had little potential for promoting well-being; characterised by the time and task-oriented nature of care, carried out as quickly as possible and with minimal interaction. I have described *damaging interactions*; in which malignant social psychology featured and which had the potential to cause ill-being, and *abusive interactions*; in which severe forms of malignant social psychology featured. All of these interactions, to varying degrees, caused participant isolation, decreased their well-being or actually caused ill-being.

In the next section, I will describe interaction types that I observed during creative sessions.

Interactions during creative sessions

OT staff (sometimes accompanied by student OTs) and the art therapist facilitated weekly creative sessions in the three wards. I saw different ways of interacting, depending on who facilitated the session and I will describe these below. Of Kitwood's (1997) elements of positive person work, *recognition*, *facilitation* and *celebration* featured regularly. However, I observed other elements of interaction, which seemed to be important in maintaining or raising

well-being: *offering choice* and *allowing time*. I will start by describing a way of interacting, which was unsuccessful in promoting participant well-being: *minimal interaction*.

Minimal interaction

Michael, the art therapist worked in ward 1 and occasionally in ward 3. His approach differed from that of the OTs. Here, from my fieldnotes are my thoughts following a session in ward 3 in which Michael and Nicole, an inexperienced OT, worked with the men:

> *I would really like it if they interacted a bit more with the men... But this is the way Michael works, he has told me that he does not believe in interfering with the process, preferring to allow the men to freely express themselves with minimal input from him.*

Michael told me that he knew little of dementia and his body language and lack of engagement reflected this. In the video-footage, during the sessions in ward 1, he leans away from Edward, he stands over him, he asks a question but does not wait long enough for him to reply *(outpacing)* and he *disempowers* him by putting paint on his brush for him.

Florence needed skilful positive encouragement and engagement in order to draw her from her isolation. The one time she agreed to participate in a creative session, Michael did not provide this for her and she remained disengaged, and left after five minutes.

However, in ward 1, Michael worked alone; often with five or six men and women and he struggled to provide adequate support for each participant. He was unable to provide Edward and Florence, who required the most support, with the level they needed in order to participate more fully and this, along with his inexperience of working with people with dementia, could have contributed to the unsatisfactory sessions.

Recognizing participants

Recognition occurred during all the creative sessions; Michael and the OTs addressed all participants by name and acknowledged their talents.

One time, in ward 2, Nina (trainee OT) was working with Hannah and Hannah had been drawing with intense concentration. She came to a natural end and Nina offered to show Hannah her painting. She held it back for Hannah to admire. *'Very good'*, Hannah said, pointing at it and smiling. Here, Nina recognised Hannah's talent and celebrated it with her; raising Hannah's well-being.

In ward 3, John and William had both played golf and, during one session, the conversation turned to golf; favourite golf courses and their proficiency as golfers. Although John's responses were weak and limited to one or two words, his facial expressions indicated pleasure as his skills as a golfer were recognised. William also spent some time animatedly discussing with Nicole (OT) the courses he had played on and revelled in the recognition that he received.

The OT staff recognised Bill's love of music and, during every session, they reinforced this by listening to him, reminiscing with him and sometimes joining in when he sang. On these occasions, Bill's well-being rose.

Facilitation

Here, people with dementia are enabled to do what they would otherwise have been unable to do; by the provision of those parts of the action that are missing (Kitwood, 1997). By offering their support in the form of scaffolding (Wood at al., 1976) or turn-taking, OT staff built up participants' self-confidence to the extent that they were able to create a painting.

In ward 2, Mary brought her apprehension and anxiety from the ward into the sessions and would usually start with expressions such as:

> *'What shall I do, darling?'*
>
> *'Now what am I supposed to do?'*
>
> *'I don't want to make a mess.'*

She usually required support and reassurance during the first part of each session but the supportive environment, in which she was reassured with immense patience, always reduced her anxiety and she always managed to paint and take pleasure in the process and the product. During one session in which Nicole drew, taking direction from Mary, there came a turning point:

> *… when Mary starts to colour in the petal of a flower, following the shape of the petal. This is the first solo effort and is praised by Nicole… and Mary chuckles, bashfully.*

Here, Nicole heavily supported Mary at the start of the session and withdrew her support bit by bit, akin to Wood et al.'s (1976) idea of scaffolding in child development. Mary's self-confidence grew to the extent that, near the end, Mary felt able to work unaided and her well-being increased.

In ward 2, Hannah also often required support and encouragement at the start of the sessions as she brought her anxious state from the ward into the session. One time Hannah and Karen (OT) were working together. Hannah drew an oval with red paint. She handed her brush to Karen and asked her to paint, so Karen drew a little circle within Hannah's oval. Then, looking at Hannah, she held out the brush towards her and said:

> *'I've had a go, so it must be… your turn!', Hannah says 'good', gesticulating with her hands and giving a laugh full of feeling. After a few minutes admiring the colours in the paint palette, and after a few more words of encouragement, Hannah starts to paint.*

During this interaction, with Karen's encouragement in the form of turn-taking, Hannah moved from uncertainty to self-assurance and her well-being rose as she started to paint more independently.

In ward 3, William sometimes required support, particularly with transferring an idea onto paper. One day, he wanted to paint a Saltire but he struggled to draw the intersecting lines to his satisfaction. Nicole, spotting this, gently offered to help him and redrew the angle of one of the lines. William was then able to complete his Saltire independently.

These examples show that facilitation; offering support by scaffolding or turn-taking is a skill that requires flexibility, a sympathetic stance and intuitive timing. With these skills, the OT staff were able to draw from participants latent or forgotten skills and to raise their well-being.

Offering praise and fostering celebration

Kitwood (1997:90) describes *celebration* as occurring in a convivial atmosphere, where the moment is experienced as intrinsically joyful. During the creative sessions, celebration often occurred alongside offers of *praise* from OTs.

Whenever Eddie worked with the women in ward 2 he would praise their efforts and hold up their work for them to admire. Mary was always pleased with her work and responded well to Eddie's praise. Here from my fieldnotes is what happened during one session:

> *Every so often Eddie asks her if she would like to see her work properly and he holds it up for her to look at. Her pride and pleasure is lovely to see and Eddie's praise for her is heart-lifting. Several times, Mary says: 'oh, that's lovely' or 'I like this one' and near the end she says as she admires her work: 'that was very clever of me….I meant, I did it well.'*

Here, from ward 3:

> *William spends an hour at the session; painting, concentrating and chatting in the relaxed calm atmosphere. He receives praise for his work and is bashfully pleased.*

Celebration occurred in the pride that participants expressed in their work and in their praise of each other's work. For example, from ward 2:

> *… Mary was pleased, surprised and proud of what she had achieved; she also spontaneously admired Hannah's painting.*

Here, from ward 3, is a rare moment of celebration between participants:

> *John leans over and shows his painted piece of fur to Bill. Bill looks at it and says: 'Oh, that's very nice, that'.*

In the daily monotony of ward 3, there were few opportunities for light-hearted, spontaneous fun and celebration. But, for an hour, once a week, those who took part in the creative sessions could have fun and laugh together. One day William had been painting; he started to fold his piece of paper and Nicole asked him if he could make an aeroplane. Here, from my DCM notes is what happened:

> *He nods… and begins to fold the paper into an aeroplane. Nicole and Michael also try to make one and Nicole hands her attempt to William who takes it and flies it to Michael. Michael flies it back and there is lots of laughter.*

Bill's expansive, convivial interactions with OTs and fellow participants, as described below, are typical of the celebratory mood of the creative sessions in ward 3:

He spends the next hour at the session; drawing on Perspex and on paper, talking, singing, reminiscing, performing for the camera and occasionally waving at me.

When I showed William downloaded footage of his participation in a session, he expanded on the importance of celebration; possibly not only during creative sessions, but every day:

'…you ..should ..in the end take as many chances as you can, to play about..'

Offering choice

Kitwood (1997) does not include *offering choice* as an element of positive person work; however, this seemed to be an important element of interaction during the creative sessions. Participants were given very little choice in the wards; in terms of what and when to eat and drink or when to go to the toilet, but during creative sessions, they experienced choice in different forms. They could choose whether to paint or not, what colour paper to paint on, what medium to use, what colours to chose and when to stop painting. For a short while, it seemed that they had some control in their lives.

Allowing time

Although Kitwood (1997) does not include *allowing time* as an element of positive person work, this seemed to be an important contributor to the relaxed, industrious ambiance of the sessions. In contrast to the interactions in the wards, there was a very different pace to the creative sessions. There was no rush, no hustle and bustle and the atmosphere was calm and relaxed. The OTs

gave participants time; to answer questions, to make choices, to work at their own pace or even just to sit and observe.

One day in ward 3, at the end of a session, John decided that he wanted to keep painting the rows of 1s that he had been concentrating on. The OTs; respecting his wishes, allowed him to continue:

> *So he continues for another 10 minutes until he has drawn his rows of 1s to the bottom of the page.*

On another occasion, when John had spent time cutting out shapes from furry material:

> *Nicole gives him the fur to touch and talks about how soft it feels and John spends some time stroking it.*

Here, Nicole fostered a calm, relaxed interaction and, not being fixed to a time schedule and not rushing to complete a task, she allowed John to manage the duration of the interaction; a rare occurrence in the ward.

Summary

In this section, I have described ways of interacting that I observed during creative sessions. I have described how Michael's interactions were often minimal and sometimes unsatisfactory, particularly in ward 1, although I have suggested reasons for such interaction. I have described how a celebratory mood prevailed during the sessions in wards 2 and 3. OT staff recognized participants, offered skilled support and choice, allowed time and praised their work; all contributing to increased participant well-being.

Participants' levels of well and ill-being

Sustained positive interactions occurred most often during creative sessions, whereas a range of negative interactions were more likely to occur in the wards. Participants more often experienced well-being during positive interactions and ill-being during negative interactions. Table 3, below, gives participants' average WIB values before, during and after creative sessions. WIB values of those who did not take part in any creative sessions provide useful comparative data. See also Appendix 12 for participants' individual WIB values.

Table 3. Average WIB values of participants

	No. of creative sessions attended	Total time before session	2hrs before session	1hr before session	Creative session	1hr after session	2hrs after	Total time after	Overall WIB value
Ward 1									
Edward	2	+0.8	+0.8	+0.9	+1.0	+1.5	+1.1	+1.1	+1.0
Florence	0								+0.8
Nora	0								+0.8
Ward 2									
Mary	4	+1.1	+1.1	+1.1	+2.5	+1.6	+1.1	+1.3	+1.3
Hannah	5	+0.4	+0.4	+0.6	+2.5	+0.9	+0.9	+0.9	+0.9
Isabel	4	+1.1	+0.9	+0.9	+2.4	+1.4	+1.0	+1.3	+1.3
Brenda	0								+0.8
Kate	0								+0.6
Ward 3									
Bill	4	+1.0	+0.8	+1.0	+2.6	+1.2	+1.8	+1.6	+1.5
William	3	+0.9	+0.8	+1.0	+1.5	+1.4	+1.2	+1.3	+1.3
John	5	+0.8	+0.7	+0.9	+1.9	+1.4	+0.9	+1.1	+1.3
Charlie	0								+0.4
Paul	0								+0.3

As seen in Table 3, participants' average WIB values increased during creative sessions, but deteriorated in the two hours following the sessions. Those who did not take part in any sessions had consistently lower average WIB values than those who did take part in creative sessions. In the following two sections, I

will describe participants' observed levels of ill and well-being and link these with interaction types that they experienced.

Ill-being resulting from negative interaction

Indicators of ill-being are unattended sadness or grief, sustained anger, anxiety, boredom, apathy or withdrawal, despair and physical discomfort or pain (Bradford Dementia Group, 1997:5). I observed all these indicators of ill-being, often with several indicators occurring together. I am adding one more indicator of ill-being to this list: *interactional destitution*, to highlight the damage that extreme isolation caused to some participants and I will turn to this first.

Ill-being as interactional destitution

I defined *interactional destitution* as occurring when participants were on their own for very long periods, with little or no contact from ward staff. The extreme isolation that these participants experienced resulted in ill-being.

In all the wards, as documented in my fieldnotes and DCM notes, those least able to initiate or sustain social contact experienced highest levels of isolation. These were the participants most at risk of interactional destitution. Here is part of the Individual Care Summary from Brenda's sixth map, which is a typical example of the level of ill-being she experienced because of staffs' failure to engage with her:

> *Brenda has walked a lot today (61% of the time) and for 20% of the time she has been in ill-being. She can become disengaged while walking... There were no occasions when someone tried to engage with her for any length of time and this has added to her isolation.*

Kate also experienced similar levels of interactional destitution. Here, from part of the Individual Care Summary from her fifth map:

Kate's day was isolated and she spent 25% of her time socially disengaged and 20% sleeping. This means that nearly half of her time was spent without any social contact. This is reflected in her low WIB value: +0.4.

Hannah experienced isolation when she shut herself off and disengaged:

Hannah is sleeping. She sits with her head nearly touching her knees, as if she wants to close off to the world. It makes her look so small.

Of the men in ward 3, Charlie, Paul, Kevin and John spent long periods sitting or walking in isolation and sometimes in distress. Here is part of the Individual Care Summary from Charlie's third map, in which his WIB value was +0.4:

This has not been a good day for Charlie. He has spent 71% of his time in isolation and 27% of his time in ill-being. At times, he was distressed but no one noticed.

Charlie's isolation seemed to be reflected in his pattern of walking, which he engaged in many times every day. Here, from my DCM notes:

He is walking on the spot, sitting down, then getting up again. He does this over and over: walking over to the wall or the television, walking on the spot when he gets there, turning round, walking over to the chair, sitting down and then repeating the pattern again.

When Kevin's wife was not in to visit, he often sat at the table in the sitting room, sleeping or looking around him. Here, from my fieldnotes is my observation of Kevin and Paul's isolation:

> *Kevin and Paul have had dull days. They remained sitting at the table in the sitting room for hours without any interaction except for meals. After lunch, Kevin was moved to the couch where he slept until teatime; when his wife came in.*

Further evidence for some participants' interactional destitution comes from their Positive Event Records. These are records of examples of very good care, observed during mapping, in which a need is met, potential is maximised, a deteriorating situation is turned around or a caregiver shows remarkable skill or talent (see Appendix 6 for an example).

In ward 2, Brenda experienced only three positive events during six maps (two carried out by OTs and one by ward staff) and Kate experienced only one during six maps (when a care assistant woke her up gently and made eye contact with her). In ward 3, Charlie experienced only one positive event during four maps (when a cleaner spoke to him kindly), Kevin and Paul both experienced one positive event during two maps (when an agency care assistant interacted kindly with them).

All of these examples show that the most vulnerable participants received scant positive interaction and remained the most isolated.

Ill-being as sorrow

The women often expressed *ill-being as sorrow*. In ward 1, one woman expressed her sorrow when she told me:

>*'It gets to my heart, seeing them sleeping like this.'*

Nora, whose mood had been deteriorating since I started in ward 1, often expressed her sorrow to me. For example:

>*Nora wakes up, but does not look happy. When I go to her, she says: 'I'm fed up' but she is not keen to engage with me. 'I could tell you lots of stories, but it won't help' is all she will say before she turns away.*

In ward 2, Kate, who had no articulate verbal communication, expressed herself visually. One evening, after mapping a particularly isolated day, I spent some time sitting beside her:

>*I sit with her, but there is no welcoming smile. She sits and looks at me, blinking and looking, once or twice taking my hand and holding it before deliberately putting it back on the arm of the chair. I ask her how she is and say that she's been very sleepy today, that it's good to see her awake, but I get no response. I ask her if she's fed up and her face becomes intensely sad… I stroke her arm and have nothing to say. She rubs her eyes and then a tear rolls down her face.*

This expression of silent sorrow gave me a glimpse into Kate's sense of isolation and I shared her sorrow knowing that little would change for her.

One day, Mary told me sadly:

> *'I used to be a good girl, now I'm sitting here doing nothing.'*

Here, she too expressed sorrow at her present plight, particularly her lack of occupation and her dependence.

Ill-being as anger and protest

Anger and protest occurred most often in ward 3. There were many instances of aggression, displayed by the same few men. During an episode in which two staff treated a man roughly, he displayed aggression; by shouting and hitting out several times:

> *He is angry and shouting and trying to hit out, but the staff are bigger and stronger than he is, and shout louder.*

On another occasion:

> *It's busy with walking men. One of them is irritable and leaves the sitting room. A few minutes later he is hustled back into the sitting room by two care assistants, he's protesting loudly and tries to hit out at the staff.*

For those less able or willing to hit out, protest seemed to be a common reaction. Kevin was a quiet man who sat and received tasks passively. But I saw two occasions when he protested at the actions of a care assistant:

> *Kevin is struggling to walk and the care assistant is struggling to pull him along. She manages to manoeuvre him into a chair in the corridor. Kevin is upset and rattled and looks around him… he looks at the care assistant and mutters crossly.*

Bill also expressed his displeasure when he felt he had been unjustly treated and he protested his case to his wife when she came to visit:

I can hear Bill giving out to his wife and she tells him that she will try to get him out of here.

On another occasion, when John had picked up a staff folder and was looking through it, a care assistant scolded him and took the folder from him:

Then I hear his voice: cross, protesting…

Much of the time, protest went unheeded. One afternoon, Bill told me that he had been insulted by one of the care assistants earlier in the day. Here, from my fieldnotes is what happened when Bill later tried to complain to the staff nurse about the incident:

Bill wants to speak with the staff nurse about it and is waiting for his chance. When he does catch up with the nurse, he has now changed into his ordinary clothes and is about to go off duty. Bill approaches him and says he wants to talk to him, but the nurse says: "I'm finished now, I'm finished now" and that's it. He walks away and refuses to listen to Bill.

Ill-being as anxiety

In ward 1, Nora expressed anxiety when a staff nurse told her she would be taking Nora out to buy some shoes the next day. Here from my fieldnotes:

She becomes uncertain and agitated. She looks at her slippered feet 'I must find my shoes, I can't go out looking like this', she becomes worried… 'What will I do until tomorrow?' and 'nothing, nothing to do'.

In ward 2, Hannah experienced intense anxiety in the absence of validation and reassurance by ward staff. On my most distressing day's map in ward 2, her WIB value was -0.1. Here is part of her Individual Care Summary for that day:

> *This has not been a good day for Hannah as reflected in her negative well-being score. She spent 42% of her time in distress and much of this was not attended to by staff.*

During this map, I intervened many times to comfort her, as I could not bear to see her distress. This means that her WIB value is higher than it would have been had I not intervened. I have justified my interventions in the previous chapter.

Brenda's isolation also manifested itself as anxiety. Here, from the Individual Care Summary of her fifth map, in which her WIB value was +0.6:

> *This has been a lonely day for Brenda. She has spent over half of her time (57%) walking alone, working alone, being disengaged and in anxious behaviour. 21% of her time was spent in ill-being.*

Charlie often expressed anxiety as he talked to me. One day as I sat with him, he became anxious:

> *… he starts to sob. Between sobs, I catch odd phrases: 'I'm lonely' and 'I couldn't get in'. He is really sobbing and looking at me intensely and I sit with him for about ½ an hour, listening to him and trying to understand what he is saying. He is too anxious to talk properly; all I get is his sense of anxiety, without fully understanding what it's about.*

In all of these examples, anxiety seemed to be linked to participants' experiences of unrecognised and unresolved isolation, resulting from absent or minimal staff interaction.

Ill-being as boredom

Apart from the input from the OT staff, the minister and occasionally from the students in ward 3, there was little provision of occupation in the wards. The men and women spent many restless hours seeking occupation.

In ward 1, participants and non-participants were generally mobile, but most often unstimulated. Many of them spent their days walking up and down, trying to pass the time. Here, is one account of their expressions of boredom:

> *… they are now pacing up and down the corridor. For the next 20 minutes or so the six men and women hold hands or link arms looking for somewhere to go, something to do. Frustration mounts, tempers flare and staff intervene.*

Here, from my fieldnotes from ward 2, is a typical example of the restlessness brought on by boredom:

> *Nothing is happening for the women. Several of them are walking up and down, trying doors, trying to get out….*

In ward 3, John sometimes tried to occupy himself, although the type of occupation he engaged in seemed to reflect ill-being. One day:

> *When I arrived on the ward, John was standing in the corridor facing the wall and running his fingers along it, as if drawing. When I start the map*

¾ of an hour later, he is still here, running his fingers over and over on a small stretch of wall. He spends another 25 minutes doing this.

William often sat with his head resting on the table. I reflected, one day, that his low mood must stem from boredom, because:

He does not receive any input from the ward staff: no conversations, no reminiscence, nothing.

Ill-being as boredom reflects the minimal, limited nature of staff interaction and the numbing absence of occupation in the wards.

Ill-being as defeat

The final indicator of ill-being that I frequently observed was defeat; when participants gave up and either disengaged or acquiesced.

One day, in ward 1, Florence had been roughly pulled along to the end of the corridor by two care assistants and placed, sobbing in a chair:

I go to her and sit beside her, she is still sobbing: 'Oh me me, oh me me'. I put my hand gently on her arm and try to comfort her. She twitches violently a few times. Then her body relaxes and the twitching stops. She pulls her blanket tightly round her neck and partially over her head, as if wanting to hibernate. Her eyes close, her head sinks down, she closes up within the warmth of the blanket. I leave her to sleep, a pitiful lonely sight.

Here, she seemed to respond to this traumatic experience by disengaging and shutting out the world.

One day, in ward 2, Kate decided that she did not want her tea so she left the dining room and walked to the end of the corridor where she sat down:

> *… but a care assistant comes, pulls her up and escorts her back to the dining room. Kate is no match for the power of the care assistant and she meekly goes with her.*

One evening, in ward 3, William was expectantly waiting for Eddie to take him out. Here, from my fieldnotes:

> *William is standing at the door when the staff are clearing up after tea. The care assistant is irritated because he is in the way. 'This will have to stop, you standing here on Tuesday nights, go and sit down' she tells him crossly. William, head down, moves back down the corridor.*

Another time, when staff had roughly reprimanded a man who had become irritable:

> *They sit him on a chair, but a few seconds later, he stands back up again. One of the care assistants returns with a banana and shoves bits of it into his mouth, then, pressing on his chest, forces him to sit down again. He quietens down.*

In the example below, John had been walking in ill-being for 30 minutes:

John is still walking painfully slowly and dejectedly. Then he sits down at the end of the corridor… but his head slumps and he sits with his eyes open; staring at nothing. He is sitting; stretched out and twisted, and does not look comfortable. He stirs briefly before slipping back into ill-being.

Here, after ½ an hour of isolated walking, he gives up and sits uncomfortably slumped in his chair, staring into space. He has given up trying to occupy himself.

Summary

In this section, I have described how participants enacted ill-being in a variety of ways, following absent, limited, damaging or abusive interaction from ward staff. All participants experienced ill-being to varying degrees, but Florence in ward 1, Hannah, Kate and Brenda in ward 2 and John, Charlie, Paul and Kevin in ward 3 experienced levels of ill-being that were sometimes intolerable to them, as evidenced by their distress, disengagement and low WIB values (see Table 3, page 209 and Appendix 12).

In the following section, I will describe how participants enacted well-being, and again I will link this to the types of interaction they experienced.

Well-being resulting from positive interaction

Indicators of well-being are: assertiveness, bodily relaxation, sensitivity to the emotional needs of others, humour, creative self-expression, taking pleasure in some aspects of daily life, helpfulness, initiating social contact, affection, self-

respect, expressing a full range of emotions and acceptance of others who also have dementia (Bradford Dementia Group, 1997:5). In this section, I will briefly describe expressions of well-being in the wards, although, with the exception of experiencing pleasure and occasionally expressing humour, they do not reflect indicators as described above. I will then describe two main indicators of well-being that I observed during creative sessions: *increasing self-confidence* and *experiencing pleasure and pride*.

Well-being in the wards

In the wards, although participants' expressions of well-being following positive staff interactions were usually short-lived, they were still significant for participants. Here, from my fieldnotes in ward 1, is one occasion where Florence took pleasure in the close engagement shown by the staff nurse:

> *After lunch, when the staff nurse was taking off Florence's apron, he tickled her and she giggled with enjoyment.*

Edward, who seemed to take pleasure in his close relationship with H, the care assistant, expressed well-being as pleasure and humour:

> *After lunch, I see H and Edward marching down the corridor, linking arms and laughing. I comment to H how well they seem to get on. 'He's my best pal', she says. They spend some time sitting together imitating each other and laughing. Edward looks animated…*

Sometimes, I felt that participants craved interaction and that any recognition from ward staff, however brief, was enough to raise well-being. Here, from my DCM notes in ward 2:

A care assistant arrives on duty. He greets Mary warmly and chats with her for several seconds. She brightens up considerably and her well-being rises briefly.

Another time:

A student nurse passes by. Hannah looks at him, anticipating communication but he does not notice. However, two minutes later a care assistant passes by and catches Hannah's eye. This time her attempt at communication is recognised; the care assistant smiles at Hannah and Hannah smiles back.

At other times, I felt that brief positive interactions prevented participants from slipping further into ill-being. Here, from ward 2:

Mary drifts off to sleep again but wakes up 10 minutes later; shivering. She looks around, seeking help but the care assistant doesn't notice; she slips into ill-being. Five minutes later a staff nurse spots Mary shivering and gets her a blanket, which she places kindly around her shoulders. Mary's WIB value rises to +1.0.

Another time:

Mary is still trying to stand up, but she is told to sit down by a passing care assistant. Two minutes later another care assistant comes to put on her apron for lunch. She talks kindly to her and Mary responds with a bright smile and says 'thanks a lot'.

In ward 3, Charlie was most at risk of slipping into ill-being due to his extreme isolation. Here was one occasion where a brief interaction momentarily re-established social contact, which, while not increasing his well-being, might have prevented it from deteriorating. Charlie had been walking in isolation for 35 minutes:

> *While still walking; this time towards the sitting room, Charlie encounters a care assistant. He reaches out his hand to catch her arm. She stops, looks round at him and greets him briefly before moving on.*

Summary

In this subsection, I have described how positive staff interactions in the wards increased participant well-being, as evidenced by participants expressing humour and experiencing pleasure. It seemed that, for the most isolated, any social contact, however brief, momentarily raised well-being or prevented its deterioration. However, as I suggested previously, it seemed that increased well-being was a consequence of positive interaction rather than the purpose of it. Participants' limited expressions of well-being could reflect the fact that, as positive interactions from ward staff were not specifically aimed at maximising well-being, they were generally too brief to provide any more than a brief respite from isolation.

Well-being during creative sessions

As I show in this section, participants did express well-being in a variety of ways during creative sessions, indicating that their limited expression in the wards was not necessarily due to cognitive impairment, but to a poverty of sustained positive interaction from ward staff. I will describe two main indicators of well-

being that I observed during creative sessions: *increasing self-confidence* and *experiencing pleasure and pride.*

Well-being as increasing self-confidence

In ward 2, Mary and Hannah were particularly lacking in self-confidence. Mary's anxiety seemed to stem from her realisation and her sorrow that she was no longer able to do the things that she used to be able to do and from her puzzlement at her incapacity. She expressed her anxiety by calling out and seeking reassurance but she seldom received sufficient reassurance to alleviate her anxiety. She always started the creative sessions requiring a lot of support and reassurance, but the patience of the OT staff paid off and her self-confidence always increased. On the day of her first solo effort, described previously, she continued to draw on her own:

> *Then, with more assurance, she draws a green vertical line. Mary seems surprised and pleased: 'I got by with it!' she says.*

Here, from my fieldnotes, is a summary of another creative session in which Mary expressed increasing self-confidence, along with creative self-expression and humour:

> *There is much laughter and Mary's sense of humour begins to emerge. There are some hesitant times, lots of concentration and guidance but also some times when Mary takes the initiative and decides for herself what to do.*

Hannah's anxiety was often distressing to see, and she too received little remedial care in the ward. But once she picked up a paint brush or a coloured

pencil, her demeanour always changed and she took on an air of self-confidence. I was always moved at her transformation as soon as she started to paint. I summed up my examination of the video-footage in my fieldnotes:

Her facial expressions change: becoming expressive, concentrating, taking on authority. Her confident brush strokes and the way she sizes her subject before and during painting indicate a person comfortable with her art.

Well-being as pleasure and pride

In contrast to participants' experiences in the wards, during the creative sessions there were no judgements about relative ability or reminders about inability and this meant that participants' efforts and their results were valued and celebrated.

In ward 2, the women always experienced and expressed pride in their achievements. Hannah would most often gesticulate and nod with widening eyes and sometimes said: *'good, good'.* Mary was sometimes surprised, but was always pleased and proud of her achievements:

'That's well, yeh, it's very much, yes that's right!'

Or:

'Oh, it's nice like that.'

When Isabel painted on a piece of silk with a deep red colour, she raised her eyebrows and said:

'That's good, I like that.'

In ward 3, the men worked industriously and often quietly and the OTs praised their efforts. Here, from my DCM notes is one example of Bill's pleasure and pride when he painted on a piece of Perspex:

> *He spends 10 minutes working and is pleased and proud with the finished result. Michael holds it up for Bill to look at properly and they admire it. Bill seems surprised at how good it looks and is really pleased with it.*

Another time, near the end of a session, William:

> *… receives praise for his work and is bashfully pleased.*

Reinforcing the idea of well-being as pleasure, are the following remarks from Bill and William. One evening, several hours after a creative session, Bill spotted me and said to me:

> *'I enjoyed that, over there, at the art.'*

Another day, I was talking to William about his time at the session. Here, from my fieldnotes is his response:

> *'Good does come from it', then he gesticulates with his hands moving upwards: '…brighten up'.*

Summary

In this section, I have described indicators of well-being that I observed in the wards and during creative sessions. As discussed above, participants' well-being levels were often only momentarily raised in the wards owing to the brief nature of positive interactions that they experienced. During creative sessions,

participants experienced extended supportive interactions, which increased their well-being (see Table 3, page 209) as evidenced by increasing self-confidence and experiencing pleasure and pride. Hannah and Isabel also seemed to take pleasure in the process of painting, suggesting that, while positive interactions facilitated well-being, the act of creating can also nurture well-being.

In the next section, I will describe how participants tried to maintain their well-being following creative sessions; with varying degrees of success.

Well-being following creative sessions

Following creative sessions, participants returned to the ward area, often experiencing increased well-being, but seldom able to maintain it. For example, from my fieldnotes in ward 2:

> *Isabel is quite bright now and is stretching out her apron on the table and smoothing it down. She tries to talk to a care assistant while smoothing out the apron, but she is ignored.*

On this, and other occasions, Isabel tried to engage with staff following creative sessions, but received insufficient interaction to reinforce her well-being. As I show in the following chapter, she gave up and disengaged.

Mary, also struggled to maintain her well-being, Here, from my DCM notes is an observation made following one session:

> *Mary has been brighter and more alert since the creative session and she has been trying to engage socially, but because she is not receiving meaningful responses from the staff, her WIB value remains at +1.0.*

As with ward 2, there was little recognition or acknowledgement of the men's increased well-being or brightness in ward 3. Bill and William found ways to maintain their well-being; Bill by writing pages of rhyme and William by practicing his walking. William also went out with Eddie in the evening to the social club, so it is possible that his excitement and anticipation maintained his well-being.

John did not have such resources and he struggled to maintain his well-being, even though he was always bright and wanting to engage on return to the ward area. On the occasion noted below, the contrast between the interactions from Eddie and the care assistant typifies the differences in interaction types between the two groups of staff:

> *John is bright and looking around, but there is no one to engage with him. Then Eddie arrives…as he approaches John, he spots his brightness and stops to chat with him. John's face lights up and he engages with him brightly. Eddie moves on… Several minutes later, John looks towards an approaching care assistant and smiles at him, but he receives no response.*

After the final map, I wrote about John in my field notes:

I wish I could have sat and chatted with him and maximized his brightness. No one else has noticed and life just drags on for him. The staff are sitting in the sitting room, watching television and chatting. Nothing is happening.

Interactions between participants and other patients

In this section, I will describe types of interaction that I observed between participants and non-participants which illustrates their capacity for rich, meaningful interaction. Very early on in the study, I realised that much of the warmth, compassion and sustained interaction that occurred was between participants and non-participants themselves. I also realised that some interactions were not as warm as might be assumed from first glance. In this section, I will focus on interactions which enriched participants and on interactions which caused them stress.

Enriching interactions

In ward 1, Edward's communication abilities were poor and he seldom initiated conversation. He spent much of his time in isolation. When he did engage positively, it was usually through mime; gesticulating, making funny faces and using his body to convey meaning. One day after a creative session, he was particularly social and this rare interaction occurred:

Edward and two men have been walking up and down the corridor (independently of each other)*. Edward walks towards them and stops to face them. He says: 'O Aye, how are you?' They respond positively and he smiles at them. He pats one of them on the shoulder.*

On another occasion, a similar interaction occurred, and as before, the visual contact was the most striking:

> *Edward walks down the corridor. As he passes another man, he puts a hand on his shoulder in a friendly exchange and smiles. The man says: 'all right?' and Edward replies: 'aye, aye'.*

Nora had developed a friendship with F, one of the men in the ward and they often spent time walking and sitting together. One morning:

> *… she meets F in the corridor and they greet each other. They walk to the end of the corridor and spend a few minutes looking out the window… They then continue their stroll down the corridor, this time F has his arm around Nora's waist; she smiles.*

Here, Nora and F are engaging in normal close engagement, F expresses warmth towards Nora and she receives it with grace.

Another time, I observed that:

> *Two women are trying to alleviate a man's pain, by gently rubbing his back and talking to him.*

Here, the women recognised that the man was in pain and they offered him compassion and physical comfort.

In the evenings, in ward 2, after spending many daytime hours sleeping or sitting passively, Kate often became more alert. She would walk around the

sitting room trying to pull women by their hands from their chairs. I interpreted these actions as Kate seeking social contact. There came a subtle change in her behaviour on my last day's map, when Hannah was very distressed. Kate's action seemed to reflect awareness of Hannah's distress and a concern for her well-being. Here, from my fieldnotes:

> *Kate walks over to Hannah and takes her hand and holds it, Hannah looks up at her and smiles faintly.*

She returned to Hannah several times that evening; possibly trying to offer her some comfort.

In ward 3, despite the fact that the men experienced limited and damaging interactions in the ward, at times they showed care to each other which was touching to watch. One day, Bill's wife came to visit, and they sat with another man and his wife in the little sitting room. When it was time for the wives to go, Bill took some tissues from a box and gave one to the man, and together:

> *… they stand at the window waving their tissues to their wives…Bill encourages the man to wave goodbye to his wife.*

Another time an agency care assistant was walking with John down the corridor from the dining room:

> *Bill is sitting on the chair in the corridor that John was sitting in before lunch. He offers John his chair…*

One day, when Charlie was distressed and disengaged and walking down the corridor, he met M, a fellow patient:

> *… he walks up to M who is standing in the corridor. M holds out his hand and Charlie takes it and they both look at each other for a few seconds.*

These examples show that, even in the limited environment of wards 1 and 2 and the harsh environment of ward 3, the men and women could still show consideration and compassion to each other; indicating their continued humanity in the face of isolation and ill-being.

Stressful interactions

Not all the interactions were as positive as they seemed. This was particularly the case in ward 1, which was a mixed gender ward. It was not until the fourth week of my time in Ward 1, that I became aware that what looked from a distance to be a warm engagement might actually be a heated exchange. One day most of Nora's interactions with her friend F were negative:

> *Nora says she wants to go home and make the tea. F, who is sitting with her, gets the brunt.*

My field notes also observed that Nora:

> *…has spent much of her day arguing with F. He thinks she is his wife and talks of things as if she were his wife, and she cannot make sense of it so she argues back with him. F has said that he loves Nora, and it is so clear from the look in his eyes when he sees her. His love is manifest in his patience and his loyalty, but this is detrimental to Nora because it adds to her misunderstanding and irritability.*

On several other occasions, participants engaged at cross-purposes; thinking each other was their spouse and this caused confusion and distress. It seemed to me that, because there was so little meaningful interaction between them and ward staff, they formed attachments with each other. But, it seemed that these attachments had taken on the significance of past attachments which were not in keeping with the present. I saw, however, that, despite communication difficulties and poor memory, these men and women were still capable of forming attachments, which were meaningful for them. The potential distress of these attachments might have been alleviated had ward staff engaged more with the everyday lives of their patients.

Conclusion

In this chapter, I have described two broad ways in which staff interacted with participants in the wards and creative sessions. These generally followed Kitwood's elements of malignant social psychology and positive person work. I have also described participants' responses to such interactions in terms of expressions of well or ill-being.

Ward staff engaged in some positive interactions, although they were limited in duration and potential for maintaining well-being. They also engaged in a range of damaging and sometimes abusive interactions, which caused participant ill-being. Participants expressed ill-being as interactional destitution, sorrow, anger and protest, anxiety, boredom and defeat.

With the exception of Michael in ward 1 whose interactions were minimal, OT staff engaged in sustained positive interactions during creative sessions and

these raised participants' well-being; as seen in their increasing self-confidence and expressions of pleasure and pride.

Following creative sessions, participants tried to maintain well-being with varying degrees of success but in the absence of reinforcement by ward staff, well-being gradually slipped.

I have also described how participants and non-participants interacted with each other. Here, I showed the compassion of their interactions, the attachments some participants formed and, crucially, the distress caused when staff failed to recognise when some interactions resulted in confusion.

These findings are a poor reflection on the type of care carried out by ward staff. However, they also show how sustained positive interaction can be remedial and nurturing to well-being.

In the following chapter, I will explore interaction types and Self-expression in an attempt to elucidate participants' daily experiences and in an attempt to explain why ward staff interacted in such different ways from OT staff; causing such differences in participants' well-being. You will note that I occasionally use the same fieldnote quotes in the next chapter. This is because the quote resonates both with interaction and well/ill-being and with interaction and Self-expression; highlighting the interplay between interaction, well-being and Self-expression.

Chapter 7: Interactions and expression of Self

Introduction

In the previous chapter, I discussed two distinct ways of interacting, which I observed in the wards and during creative sessions; broadly following Kitwood's malignant social psychology and positive person work. I observed that ward staff often engaged in limited and sometimes damaging interactions with participants, often resulting in participant isolation and ill-being. During creative sessions, OT staff engaged in more positive and affirming interactions, often resulting in enhanced participant well-being. I proposed that the, often limited and damaging interactions that participants experienced from ward staff, reflected poorly on the quality of care that participants received in their every day lives.

In this chapter, I will reiterate Sabat's (2001) three aspects of selfhood: Selfs1-3, and describe my observations of participants' verbal and visual expressions of Self; in wards, during creative sessions and after creative sessions. I will elaborate on Sabat's work and show that many expressions of Self were fragile, which I define as expression of Self in negative terms, in the context of ill-being. A fragile expression of Self differs from Sabat's negative expression of Selfs 1-3 in that negative expression of Self need not indicate ill-being, whereas a fragile expression of Self accompanies ill-being.

I will also introduce two new concepts along with their counterparts, which illustrate my position that the quality of a participant's Self-expression (for him/herself) depends on whether staff, through their interactions with the participant, recognise and support Self. These concepts are: *recognised Self*, *unrecognised Self*, *supported Self* and *unsupported Self*. I will suggest that ward staff do not fully recognise and therefore cannot support Self, while OT staff more often recognise and therefore support Self. Throughout this chapter, I will support my findings using fieldnotes, DCM notes and quotes from participants.

Selfs 1-3

Self 1 is the Self which expresses first person indexicals "I", "me" "myself", "mine" or "ours". This aspect of Self reflects the fact that each person has one single point of view in the world. By using first person indexicals, we take responsibility for our actions, we locate for others our experiences and feelings and tell stories about ourselves. Self 1 can be expressed verbally, for example: "That's mine" or "I like that" and also through visual expressions which would signify identification with oneself, for example: reacting to one's name being called, taking possession of an object or reacting to protect oneself. Sabat (2001) suggests that Self 1 remains largely intact in people with dementia, even with severe cognitive decline.

Self 2 comprises one's physical, mental or emotional characteristics and attributes, and also one's beliefs and desires about them. Some Self 2 attributes have long histories, for example, past achievements, while some have more recent ones, for example, the frailty that accompanies an illness. Self 2 can be

expressed verbally or visually and in positive or negative terms. Sabat (2001) suggests that Self 2 remains largely intact with cognitive decline, although it is vulnerable when others view disabilities caused by dementia as being attributable to the person rather than the illness.

Self 3 is the publicly presented aspect of ourselves: the social roles we take on and the appropriateness with which we behave in social situations. Manifestations of Self 3 could be enacting a familiar role such as wife or husband, showing regard towards another, being protective, being gracious or showing agency (Sabat and Collins, 1999). Self 3, being constructed, sustained, nurtured or changed through interaction with others is more vulnerable to damage than Selfs 1 and 2 (Sabat, 2001).

Expressions of Self 1

These involve locating oneself to others by verbal and visual means, using first person indexicals.

Verbal expressions of Self 1

In ward 1, Edward's verbal communication often made little sense to me as his words were partial and his sentences disjointed. He sometimes expressed Self 1 on the occasions that he did speak more clearly. One day after a creative session when H had been helping him, he expressed Self 1 very clearly. Here, from my fieldnotes:

> *I show her (H) the video-footage and she then shows it to Edward who watches intently. 'That's you!' says H 'Aye, I know that's me' Edward replies.*

Nora, being articulate, expressed Self 1 proficiently. She demonstrated the complexity of Self 1 expression one day when she returned with a staff nurse from the shopping trip mentioned in the previous chapter:

> *She is looking happy and bright. I go to her to say hello and ask her how she got on. 'I'm happy, happy, happy' she says, beaming.*

Here, she not only indexed herself in her discourse, but she located, to others, her happy feelings as being her own. However, she often expressed Self 1 as fragile; in which she located to me her sorrow at her present plight. One evening when participants and non-participants were fraught and restless, I approached Nora who was walking irritably with another woman:

> *Nora says "I wish I could get home, I've never been so fed up in my whole life" and "I can't get out, the doors are always locked".*

Here, Nora's expression of Self 1, in the context of irritability and restlessness was fragile.

Florence also located her feelings to me, and these too were often fragile expressions of Self, for example:

> *Florence is sitting quietly, looking fed up. "I'm scunnered", she says. She becomes restless, starts to move the cushions around…*

Participants often expressed Self 1 in conjunction with Selfs 2 or 3. For example, Edward used *'my'* to index his personal experience (Self 1) of being without his dentures (Self 2 characteristic). Here, from my fieldnotes:

Edward broke his top set of dentures the other day and he drew my attention to this by opening his mouth and feeling for his absent teeth: 'my teeth…'

In ward 2, Mary expressed Self 1 on the day she called over to me:

'Hello, it's me, Mary'.

Another day, she expressed Selfs 1 and 2 as fragile when she said sadly:

'I'm fed up, it's such a lovely day, I could be outside'.

Here, she not only located her feelings to me (Self 1), but she also seemed to lament the loss of her former independence (past Self 2 attribute) while recognising her present Self 2 state of dependence.

Hannah expressed Self 1 proficiently, although often she was in distress. On this bright occasion in the dining room:

She is facing the wall on which hangs a bold bright painting of people picking apples from a tree. Hannah looks at it and waves her hands in curvy lines: 'I like it', she says.

Isabel clearly expressed all aspects of Self, both verbal and visual and, of the five participants in ward 2, her Self seemed the most robust. She expressed Self 1 when she remarked:

'I don't like cats' or *'I'm tired'.*

Kate had no articulate verbal communication, although she would sometimes say a long, heartfelt *'uuuummmmmm'* while sustaining eye contact with me. At these times, I sensed that, through her eye contact with me and her occasional smile, she was at least locating herself to me; thus expressing Self 1.

Brenda had little verbal communication and spent hours walking in isolation. She sometimes responded with a quiet vocalization when I approached her and said her name. This seemed to be an expression of Self 1: recognising her name. Once, she was sitting with her daughter while Nina, the trainee OT played a ball game with some of the women:

> *Nina hands her a ball, which she looks at. Then her daughter starts to talk to Brenda and Brenda says very clearly: 'wait, I'm playing'.*

This was the clearest verbal expression of Self that I heard from Brenda in my time in ward 2.

In ward 3, Bill was articulate and expressed Self 1 proficiently, for example, he located himself to others and he reminisced frequently.

William had difficulty with his verbal communication due to a previous stroke and he spoke in short, sometimes disjointed sentences. He expressed Self 1 clearly, when he located his feelings to me:

> *'I'm very tired'.*

Or, when he spotted another man holding the book he had received from the mobile library:

'That's my book'.

John's verbal communication was limited to short phrases. He expressed Self 1 verbally one day when I asked him if I could take a picture of him. He replied:

'Of me?'

He also expressed Self 1 when he:

… fingered my red cardigan and said: 'I like this, I definitely like it'.

Charlie, while having difficulty speaking, still managed to express Self 1 to me in short sentences. One day, when I told him where I was from, he brightened up and said:

'Oh, I ken (know) *that place'.*

Another time he located his pleasure as being his own:

'I like to see you'.

However, Charlie was a frail, isolated man, whose expressions of Self 1 were most often fragile and sometimes accompanied by weeping:

'I'm tired', 'I'm lonely', 'I don't like it here', 'I dinnae like the people.'

As Kevin spoke only to say *'aye'*, and as Paul had no verbal communication, it was difficult to identify verbal expressions of Self 1. However, I did glimpse what I felt were fleeting visual expressions of Self 1, as described below.

Visual expressions of Self 1

Paul was profoundly deaf and had no verbal communication. Near the end of my time in ward 3, I saw what I felt was one visual expression of Self 1 and maybe Self 2. Here, from my fieldnotes is what happened when he picked up my notebook. He:

> *… is looking at the notebook, turning over the pages and holding the pen towards the paper as if wanting to write. I hold his hand and doodle and he looks at me and smiles. After several more minutes, I put my hand over his and write his name: 'Paul'. He looks at this for a few seconds and then makes a loop on the 'l' and rounds off the 'a'. I am amazed at this. Here he is, correcting my writing of his name so that it conforms to how he would write the letters. It is definitely the best expression of Self that I have seen and I am delighted and show him my delight by smiling and nodding at him.*

Here, he seemed to express Self 1 by locating his name to me, and Self 2 by reclaiming his writing ability.

Kevin's only expression of Self 1 was to respond to his name by smiling. Here, he seemed to reciprocate my reference to his Self 1 with a smile; locating to me his pleasure at being addressed by his name:

> *I find Kevin and say: 'hello, Kevin'. He smiles at me.*

Summary

In this section, I have shown that all participants expressed Self 1 to varying degrees. Some, like Edward, Nora, Isabel, John, Bill and William were proficient in their Self-expression while others, like Kate, Brenda, Paul and Kevin expressed Self 1 in subtle and sometimes fleeting ways. Some, like Florence, Hannah, Mary and Charlie seemed to express Self 1 in ways that reflected their isolation or sorrow; indicating a fragile expression of Self. For those with increasing levels of communicative or cognitive difficulty, identifying Self required astute observational and interpretative attention, which, without training, may be beyond the scope of ward staff. This has implications for how ward staff perceive Self of people with dementia and therefore how they interact with them, as I will discuss later.

Expressions of Self 2

Participants' awareness of and beliefs about physical and mental characteristics and attributes; past and present.

Verbal expressions of Self 2

In ward 1, Edward's Self 2 was clearly evident in the way he recognised the divide in freedom of movement between himself and the staff. *'**They can get out'**,* he called out after increasingly frustrated attempts to leave the ward one evening. His extreme frustration at not being able to leave arose as he seemed to recognise that his previous freedom of movement (past Self 2 attribute) had been replaced by a new unwanted Self 2 attribute: restricted freedom of movement.

Nora more often expressed awareness of her physical Self 2 characteristics. For example, one day a care assistant put curlers in Nora's hair. Here, from my fieldnotes is what happened when Nora looked at herself in the mirror when the curlers were removed:

> *Nora knows that her hair is different… she says: 'it doesn't look very great'. She knows how it should be; how she had always liked it, and now it is wrong. She pulls at it, tries to make it lie the way she wants, for over five minutes with little success; for it had been so heavily sprayed. She frowns at herself, becoming more and more disgruntled…*

Here, a physical Self 2 characteristic in which she took pride has been altered and she expresses displeasure that she no longer looks familiar to herself. Her displeasure increases as she, unsuccessfully, works to reclaim her familiar Self 2 characteristic by trying to restyle her hair, and her expression of Self 2 becomes fragile as she slips into ill-being.

Once, when I was sitting with H, Florence came and sat down beside us and we drew her into conversation:

> *The talk turns to baking. H asks Florence what ingredients she would have in her cake. After some thought, Florence agrees on flour, margarine and cherries.*

Here, H supported Florence in remembering and taking pleasure in a valued past Self 2 attribute; her proficiency in baking. I observed few other verbal expressions of Self 2 by Florence.

In ward 2, Mary was often reminded that she could not walk, even though she was able to weight bear. She was a big woman and the staff had decided that it was easier for them to use the hoist. She repeatedly asked anxiously: *'what's wrong with me?'* This expression seemed to include Selfs 1 and 2: Self 1 when she referred to *'me'* and Self 2 when she questioned her physical abilities and lamented the loss of her past, mobile Self 2. She often expressed Self 2 in such fragile ways to me:

> *She calls me over and I go to her. She tries to tell me something but her words are jumbled and she becomes upset: 'I'm failing, the words don't come…I used to be able….stories…'*

One afternoon, I decided to break the boredom by looking at a book with Hannah. She clearly expressed Self 2 in her pleasure and pride when we found a painting she had done:

> *Tucked in front of the book is a picture that Hannah drew; maybe of herself and her signature is written below the portrait. I show it to her and she wriggles with excitement and pleasure and says: 'that's good!' I tell her I reckon that she drew it and that it looks like her… and again she wriggles with pleasure: 'very good, very good'.*

Isabel expressed Self 2 to me, along with Self 1 one day:

> *After a while, she says that her back is sore so we sit back down again.*

Here, she locates herself to me (Self 1), but also references herself in relation to her present physical Self 2 characteristic: back pain.

I observed no verbal expressions of Self 2 from Kate or Brenda.

In ward 3, Bill expressed Self 2 when he reminisced about his harmonica playing days, when he spoke about not *'having the puff'* to play as he used to and when he said to me:

> *'I'm pretty poetical, you know.'*

William expressed Self 2 to one of the agency staff when they compared the colour of their eyes and hair:

> *'My eyes are grey.'*

One day, as I sat with John, he expressed Self 2 clearly:

> *He holds out his hands: 'Look at my hands!' he says, examining them closely.*

Charlie spoke to me only once about his abilities:

> *'Aye, I like to dance.'*

Another day he showed me his tattoo. Apart from these two events, I did not observe him acknowledge, either positively or negatively, his physical, mental or emotional characteristics or attributes.

I saw no verbal expressions of Self 2 from Paul or Kevin.

Visual expressions of Self 2

If Self 2 is the Self of physical and mental characteristics and attributes, this must also include characteristic facial expressions. In ward 1, Nora sometimes took on a girlish, flirtatious quality and I found it easy to imagine her as a young woman. Similarly, in ward 2 during the creative sessions, Mary occasionally displayed humour and would screw up her face in a coy expression, which soon became familiar to me. Isabel had a way of quickly raising her eyebrows and widening her eyes as if to emphasise a point. In ward 3, John sometimes smiled at me in a particular way and I wondered whether he thought I was his daughter. Although I did not know participants from their younger days and therefore could not be sure that these expressions were uniquely theirs, I sensed that these familiar, fleeting visual expressions displayed a Self 2 of unique personal expression.

Other visual expressions of Self 2 seemed related to awareness of physical characteristics. In ward 1, Nora appeared to be conscious of the poor state of her nails, for she would often sit and pick at them. This could be an indication of her awareness of the difference between a valued past Self 2 characteristic (healthy nails) and a present Self 2 characteristic (neglected nails):

> *I walk down the corridor with Nora. She is picking at a fingernail. We inspect it. Her nails are very long, and she has tried to bite some of them down.*

Florence seemed to express a physical Self 2 visually to me one day:

She is gesturing to her hair. I ask her if she wants it brushed. It might have been an 'aye'. I ask a student nurse for a hairbrush and she goes and gets one for me. I brush Florence's hair and she seems pleased.

Kate seemed to acknowledge my recognition of her Self 2 one day when I admired her smile:

She puts her hand up to my face and touches it, smiling intensely. I admire her beautiful smile and she moans, her eyes squeeze up and her lips purse tightly.

Once, in ward 3, I saw Paul express what might have been a visual Self 2: recognition of his physical characteristics:

Paul is now sitting beside me. I hold out my hand to him and he takes it. His hand is so cold; his fingers are purple and his nails are a grey/blue. I say: 'Oh, your hands are so cold', and I rub my hands together and he copies me. We rub our hands together and he smiles.

Summary

In this section, I have described my interpretations of verbal and visual expressions of Self 2. As with Self 1, there was a wide variation in expression, with some participants showing proficiency and others expressing Self 2 in subtle, sometimes fleeting ways. Most expressions of Self 2 concerned physical characteristics rather than mental attributes or achievements. This may have been because there was limited opportunity for participants to reminiscence with people who were familiar with participants' past Self 2. Some visual

expressions seemed to reflect participants' unique facial characteristics and could have drawn on past expressions of Self. Some expressions of Self 2 seemed to reflect participants' recognition of and sorrow for loss of valued Self 2 attributes and at these times, their expressions of Self were fragile. Those least able to initiate or sustain communication had fewer opportunities to express Self 2 in their everyday ward lives.

Expressions of Self 3

Participants' personae and social roles, which require the co-operation of others for their expression.

Verbal expressions of Self 3

In ward 1, Edward expressed Self 3 when the visitor came with her dog, Millie, as described in the previous chapter. Here, from my fieldnotes:

> *Edward instantly lights up and becomes more animated than I have seen him. He bends down to pat her, follows her up the corridor and tries to talk to her… Edward takes the lead and off he goes with Millie, smiling and looking relaxed. He continues to talk to her and to smile.*

As he strode down the corridor with Millie, re-enacting his past dog-walking days, I caught a glimpse of how he might have been and how he could continue to be. I saw him react like this twice more: calling over to a little girl who came to visit her grandfather and becoming animated and talkative when Florence's granddaughter came with her dog. On these occasions, Edward clearly expressed Self 3.

In her everyday ward life, Nora often expressed sorrow that she no longer lived in her own home. On these occasions, she expressed Self 3 in fragile ways:

'I'd like my own wee kitchen and room'.

However, once, in an encounter with F; with whom she had a special friendship, I sensed the Self 3 that Nora was and could be again, if given recognition:

We have a great banter. When Nora is like this, I can see the young woman in her: flirtatious, funny, light-hearted…The mood is sustained for a few more minutes and it is a joy to be a part of. Soon they are away down the corridor again and the moment is gone.

In ward 2, when Hannah was alone, she expressed Self in increasingly fragile ways: whimpering, rocking and looking around anxiously, but when someone engaged with her she would become animated and gesticulate with her hands. On these occasions, she seemed to re-enact a social Self 3. One day, when I chatted with her, she seemed to express a social Self 3 to me (along with a visual Self 2):

I say to her: 'you've got lovely eyes, Hannah'. She puts her fingers around her eyes, and peers out through the holes as if looking through binoculars and I copy her, we both laugh. 'We should get together, we could have fun' she says.

I saw no verbal expressions of Self 3 from Kate or Brenda.

In ward 3, Bill expressed Self 3 frequently. For example, one day he said *'excuse me'* as he suddenly got up to go to the toilet. Here, he acted with grace; appropriate for an abrupt leave-taking.

William's dominant persona was sexual and almost all of his interactions involved verbal or tactile attempts to engage sexually. While this expression of Self may have emerged as William's dementia progressed, it did seem to be an important and persistent aspect of his present Self. However, ward staff attributed this way of interacting to William rather than to his dementia and gave him little opportunity to express a social Self 3 in the ward; thus stigmatising him and banishing him from normal social contact. However, one day, he managed to construct a social Self 3 with the minister and, with her non-judgemental, matter of fact approach, he sustained a socially appropriate interaction.

> *William goes into the sitting room and the minister greets him. She asks him where he would like to sit and points out some free chairs. He decides on one and she joins him and, with the agency care assistant, they talk about St. Andrew's day. William is in great form, and enjoys the chat.*

Most of Charlie's expressions of Self were fragile, however I observed one conscious, positive expression of Self 3, along with anxious expressions of Self 1:

> *Charlie spots me and comes over to me with his hand out-stretched. 'Will you come with me?' he asks and I do. We walk up and down the corridor together... 'You'll stay, you'll stay?' he asks and I tell him I'll stay for a bit.*

> *We approach Charlie's chair and I gesture for him to sit down, but he*
> *says: 'no, you', so I sit down.*

Here, Charlie was being gracious in offering me his seat; co-constructing with me a social persona.

I observed no verbal expressions of Self 3 from Paul or Kevin.

Visual expressions of Self 3

In ward 2, Kate visually expressed Self 3 more often than Selfs 1 and 2. On many occasions, she pulled at other women's hands or she took my hand and led me up and down the corridor. Here, she reached out for contact and expressed a need to engage socially. On several occasions, when Hannah was distressed, Kate approached her and seemed to be trying to comfort her. On this occasion, Kate initiated social contact with Hannah and received it from another woman:

> *She walks over to Hannah and takes her hand, she blinks at her and*
> *Hannah responds by smiling and nodding at her. While Kate is holding*
> *Hannah's hand, another woman comes over and takes Kate's hand and*
> *Kate responds with an 'mmmmm'.*

This indicates that, despite her communicative and cognitive difficulties she was able to engage reciprocally with others. This was evident on another occasion when I was walking with Kate and singing a song to her. Her response seemed to be a communication of gratitude:

When I am finished, Kate pushes me slowly towards a chair and sits me down in it, then she slowly bends down and rubs noses with me, smiling.

Kate also expressed Self 3 on the occasion noted below, in which she expressed a desire for comfort:

I sit on the couch beside Kate who is wide-awake, and I chat to her and try to engage with her. I have my hand on my knee and she takes it and manoeuvres it so that my arm ends up around her shoulders, then she settles against me and I settle down with her.

Brenda's visual expressions of Self 3 were subtle and fleeting. Once, when she coughed she put her hand over her mouth, expressing a polite persona. I observed another expression of Self 3 on the two occasions that she leant over to kiss her husband. Here she seemed to be enacting the role of wife.

Brenda's dominant expression of Self 3 was in her pattern of isolated walking. Here, she seemed to epitomise the fragility of a social Self that comes with isolation:

Brenda is still walking…she looks flushed and agitated. She continues to walk, sometimes in ill-being for 1½ hours. On one occasion, she is walking in the little sitting room and she walks towards the wall. She stops at the wall and goes no further, but her feet are still moving on the spot, as if she is trying to continue on her way.

In ward 3, I observed few expressions of Self 3 during John's limited interactions with the ward staff. However, in my interactions with him, I observed several visual expressions of Self 3. One day when we had been walking along the corridor, he expressed a polite Self 3 persona:

> *He looks like he is tiring so I ask him if he would like to have a seat. He says he would so we head towards the door of the sitting room. As we approach it together, he gestures for me to go ahead of him and I say: 'thank you' and enter first.*

Every day John greeted me with a warm smile and sometimes a kiss and this was a clear expression of Self 3. One day his gentleness was profound:

> *We sit together for a while. At one stage, he leans towards me and very gently strokes my fringe back off my forehead. He looks at me intently and then, when he is done, he smiles and wriggles his shoulders.*

Another time, John took my pencil and put it behind his ear. This tiny action, seemingly done automatically, seemed to be reminiscent of his days as a joiner.

When Charlie smiled when greeting me, his face lit up and these seemed to be his most regular positive expressions of Self 3: a social persona. However, as with Brenda, his dominant visual expression of Self 3 was fragile; reflected in a particular pattern of walking which he engaged in many times every day, and which seemed to reflect his social isolation:

> *Charlie is walking at the end of the corridor; up and down within a small area, to the staff room door, back again, around the wall, in front of the*

television. He sits in the armchair for a few seconds, then he gets up and does it all over again; over and over. This goes on for 20 minutes.

As with Brenda, this pattern of walking did not seem to have an air of pleasure or purpose to it. Both Charlie and Brenda walked in social and physical isolation and sometimes seemed to be unaware of their surroundings. Sometimes they muttered or grimaced and seemed to be in ill-being. As one does not normally walk in such a repetitive and isolated way when in well-being, I interpreted these expressions of Self to be fragile.

Here, from my fieldnotes is an account of a rare connection with Paul, which seemed to be a visual expression of a social Self 3:

Paul is occasionally bending down and licking the table. When I touch him, he looks at me with his mouth wide open. He gives me a wide slow smile and his eyes come alive. Even though he does not communicate verbally, I see communication in his eyes.

When Kevin's wife came to visit, he responded to her by smiling and he sometimes tried to communicate with her (social Self 3). He often greeted me with a smile and a raising of his eyebrows which I understood to signify a greeting. I also saw an expression of Self 3 one day after lunch, in which he seemed to be trying to preserve his acceptable social persona:

Kevin's clothes are covered in soup and he is trying to clean them up.

Summary

In this section, I have described participants' verbal and visual expressions of Self 3 during interaction with and observation of them in the wards. All participants expressed Self 3 to varying degrees; however, most of them occurred in interaction with others apart from ward staff: visitors, the minister, each other or myself. Participants often expressed Self 3 in fragile ways, which seemed to reflect their experiences of isolation and ill-being, particularly those who were least able to initiate or sustain communication due to mobility or cognitive difficulties.

Expression of Self during creative settings

In this section, I will describe expressions of Self, which I observed during creative sessions. I will also describe my observations of *unexpected proficiency*, which I define as: activity during a creative session, which I did not observe in the ward and which struck me for its dexterity, initiative, expression or precision.

In ward 1, although Edward only spent short amounts of time at each session (ranging from 5-18 minutes) and Michael, the art therapist did not fully support him, as discussed later, he expressed a different Self during the creative sessions than in the wards. He showed unexpected proficiency by laying out his pens in neat rows and by writing lines of letters and numbers with efficiency and concentration. Edward had been, at various times, a policeman, a post master and a bed and breakfast proprietor. During these short sessions, he took on a workman-like air that was not evident in the ward and it was as if, here, he could express something of the working-man in him (Self 3).

Florence took part in a session only once and, because Michael did not support her, it was unsuccessful. Nora, who was becoming increasingly despondent, declined to take part in any session.

In ward 2, Mary often expressed anxiety at the start of the creative sessions, which showed her lack of self-confidence:

> *'I'll make a mess', 'I'm no good', 'I could never do that.'*

As the sessions progressed, her expressions moved from negative to positive, from: *'oh, no I couldn't'*, to surprise and pride in her achievements. Here, from my fieldnotes is an occasion in which Mary's expression of Self 2 has moved from fragile to robust:

> *Eddie…holds it* (her painting) *up for her to look at. Several times, Mary says: 'oh, that's lovely' or 'I like this one'. Near the end of the session, she says as she admires her work: 'that was very clever of me….I meant I did it well'.*

One time she showed unexpected proficiency which seemed to surprise her. She had started the session requiring much support and reassurance. Here, from my fieldnotes is what happened when Nicole (OT) supported her in reclaiming a valued Self 2 attribute – independent activity:

> *There comes a turning point when Mary starts to colour in the petal of a flower, following the shape of the petal. This is her first solo effort and is praised by Nicole. Then, with more assurance, she draws a green*

vertical line (the stem of the flower she and Nicole have drawn). Mary seems surprised and pleased: 'I got by with it!'

Hannah presents the most striking example of the effect on her Self-expression of taking part in the creative sessions. In contrast to her almost constant distress in the ward, her Self 3 (artist persona) re-emerged and the transformation was sometimes quite spectacular; she would blossom again for a short while and experience a little part of the artist Self she had once been:

> *…the creative sessions are very good for Hannah, they allow her to express her creative Self, which was always very important to her. In the past few months, as she has become frailer, her paintings have taken on a simplicity, but you can still see the painter in them. During the sessions, her facial expressions change; becoming expressive, concentrating, taking on authority…*

Here, from my fieldnotes is a description of Hannah's proficiency (Self 2) as an artist (Self 3); a proficiency and confidence not seen in the ward:

> *At one stage, Karen (OT) hands Hannah a paintbrush and Hannah draws a bold oval, without faltering.*

Isabel often expressed an intellectual Self 2 during the sessions, for example:

> *Isabel spends most of her time at the session writing: 'Rick Lake'… and embellishing her writing with lines underneath. She reads the writing on the paintbrush, counts the colours in the tray...*

Once, when she knitted with Michael's support and turned the needles round of her own accord, she showed unexpected proficiency as she seemed to reclaim a past Self 2 attribute; her skill in knitting:

Initially Isabel needs to be reminded to turn the needles around after each row. Isabel starts to count the stitches… now her focus is on counting and keeping track of the stitches. She counts in twos and paces her counting according to how fast she is knitting. Then, she turns the needles around without being prompted and continues to do so until the session finishes.

Kate and Brenda did not take part in any creative sessions: Kate because she was usually sleeping and could not be roused and Brenda because she was not sufficiently interested. I do not know whether they might have expressed Self in other ways too.

In ward 3, Bill strikingly expressed Self in his paintings:

He spends a long time drawing isolated little images on the page, until the page is full of them. There are symbols and shapes like islands, some pictures that he identifies as certain things: an open envelope, a treble clef and a flying kite, and some that even he doesn't have names for.

It seems that the creative sessions allowed him to freely express, through his random shapes and symbols, something of himself that could not be expressed within the tight constraints of the ward.

During the creative sessions, William worked industriously and was relaxed and jovial. He did not display any sexual behaviour. He expressed all aspects of Self positively, particularly Self 1 when he reminisced about his love of aeroplanes. One day:

> *William pulls over a piece of clear white paper and starts to draw on it with an acrylic crayon. Then he begins to fold it and Nicole asks him if he can make an aeroplane. He nods and begins to fold the paper into an aeroplane. Nicole and Michael also try to make one and Nicole hands her attempt to William who takes it and flies it to Michael. Michael flies it back and there is lots of laughter. Then William and Nicole start to talk about Concorde. William becomes animated and expressive as he gesticulates the shape of the aeroplane.*

One time he gave Bill a thumbs-up sign in recognition of the work he had done and, after another session, he helped to tidy the table; both social expressions of Self 3.

When the OT staff praised John's work and he smiled at them, he expressed pride in his achievement (Self 2). He also expressed Self 2 during a creative session when he said: *'damn'* one day as he painted. Here, he seemed to express frustration at his present Self 2 attribute, which was at odds with his valued past Self 2; in his days as a joiner, he would have strived for accuracy. He also expressed Self 3 one day during a creative session when he responded to Nicole:

> *'Oh, I had several jobs.'*

One day, he displayed unexpected proficiency as he reclaimed a past Self 2 attribute; dexterity in using a scissors:

> *The session involves furry fabric: cutting out shapes and gluing them onto coloured paper... John cuts out pieces of fabric, using a scissors!*

Later in that session he handed the scissors back to Nicole, having manipulated it so that the handle pointed towards her, an example of a gracious Self 3.

Charlie, Paul and Kevin did not take part in any creative sessions and I had no opportunity to explore whether they might have expressed Self in other ways too. As in ward 2, because the OT staff received no support from the ward staff, they could not meet these participants' increasing needs for one-to-one support, while still meeting the needs of those who wished to participate in the sessions. This, while being a limitation of the study, also reveals the paucity of positive interaction these participants experienced in their everyday ward lives.

Summary

In this section, I have described how participants expressed Self in a variety of ways during creative sessions, some of which were not seen in the wards. In particular, I have described instances where participants behaved with unexpected proficiency, which seemed to emerge in parallel with support received from OT staff. On these occasions, it seemed that they reclaimed, for a short while, past Self 2 attributes. It seems that Edward, Hannah and Bill used creativity as a means for Self-expression, while Mary, Isabel, William and John expressed Self through their interactions with OT staff. This shows that Self-expression can either flow from creativity or be expressed in interaction which

has as its premise the desire to maximize each person's potential (Self 2). Creativity then, can be a means for Self-expression or a catalyst for interaction that promotes Self-expression.

Expression of Self after creative sessions

On return to the wards, participants tried to express or co-construct Self (Snyder, 2006), but with minimal recognition from ward staff, Self-expression was most often a solo effort.

In ward 1, after a session, Edward managed to enact his workman-like persona with marker pens he had taken from the session.

> *He spends some time arranging two markers in his shirt pocket.*

Later, at lunch time:

> *Edward spends some minutes positioning and re-positioning the markers in his pocket and aligning them to sit side by side.*

Here, he used props to enact a Self 3 (his working-man persona), and they served him well for a time.

In ward 2, following the sessions, participants also tried to find occupation that perpetuated their increased motivation or self-confidence. One day, in the sitting room after a session, Hannah seemed particularly motivated. She stood up and walked with her Zimmer out of the room and down the corridor:

> *I am looking at this thinking 'wow, I've never seen her walk of her own accord before'. She heads off down the corridor and away round the*

corner towards the bedrooms. This is a long walk for her. She stops at the end of the corridor where the couch is. She sits down and picks up a magazine that is lying there. She reads it.

This happened on one other occasion following a creative session and they were the only two times I saw Hannah walking of her own accord and finding occupation. On these occasions, it seemed that her increased self-confidence in the creative sessions stayed with her after the session, allowing her to reclaim past Self 2 attributes (walking independently and reading) for a short while.

Isabel was also motivated to take control over her boredom on a few occasions and, like Hannah, found occupation by reading a magazine that was lying on a table. Magazines were a rare sight in the ward and both Hannah and Isabel found and looked at the same magazine after the same creative session.

Another time, Isabel found a list belonging to one of the staff and seemed to enact Self 3; taking on an official persona:

She returns with a list of patients' names and she reads them aloud. She walks to some of the women, reading out the names from the list, looking up and smiling at them.

After another session, finding no-one to talk to and no props for Self-expression, she gave up and withdrew socially. Here, from my fieldnotes is my observation of this occasion:

This is the problem: Isabel is bright and chatty and she is trying to engage, but there is no one willing or able to engage with her… Isabel gives up. She walks to the end of the corridor and sits up beside Kate and another woman who occasionally shouts out loudly. Up here, she has no one to talk to and soon she sleeps.

Mary sometimes tried to express her new Self 2 attribute of increased self-confidence but, without support from ward staff, she was unable to and soon gave up.

She tries to stand, holding onto the arms of the chair, she is teetering forward, looking round for help. There is no one in the room. She sits down…

Another time:

Mary is bought back into the sitting room on the hoist. She sits in the corner of the sitting room, on her own…Then she looks around her brightly, smiling, but there is no one to talk to and she cannot go anywhere, so she has to remain by herself. She remains bright and looks around her smiling for over 10 minutes. She is relaxed and ready to engage (Self 3). There are three care assistants in the room yet no one notices… Soon her well-being drops to +1.0.

It was while watching Mary's unsupported attempts to express her reclaimed Self 2 attribute and her unsuccessful attempts to enact her social persona after

the creative sessions that I realised how dependent participants were on others to recognise and support Self. I will discuss this more fully in the next section.

In ward 3, as there was little recognition or acknowledgement of the men's Self-expression, they had little opportunity to express or co-construct Self with ward staff after the sessions. Bill, who seemed most able to express Self, managed to sustain Self 2 by writing lines of verse. William sometimes practiced walking in straight lines as if trying to reclaim a past Self 2 attribute to replace his present mobility difficulties following a stroke:

> *He starts to walk, very deliberately and with great concentration across the room. He stops, turns around and repeats the process several times. He walks, taking big steps, placing one foot directly in front of the other, and supporting himself with his stick.*

When I asked William whether he was practicing his physiotherapy exercises, his response seemed to indicate his increased self-motivation resulting from the sessions:

> *… he says 'no'. He says he is practicing walking in a straight line. Then he says: 'the art helps me'.*

John often left the sessions eager to engage with someone (social Self 3) but seldom managed to. Here, from my fieldnotes is what happened one time after particularly unsuccessful attempts to co-construct Self 3 with passing ward staff.

He spots me in the corridor and comes towards me; beaming, bright smile and he sits down in the armchair beside me. 'That's better', he says.

John recognised that I was someone with whom he could enact a social persona and, in the absence of anyone else, he used me as a co-constructor of Self 3.

Summary

In this section, I have shown how, on return to the wards, participants tried to express aspects of Self that they had expressed during the creative sessions; with some participants successfully using props to support Self-expression. In the absence of sufficient recognition or support of Self-expression by ward staff, some either reached out to me or eventually gave up and withdrew. This section shows how contingent all aspects of Self are on the recognition and support of others and I will now explore this crucial point in greater depth.

Interaction types and Self

As seen in the previous chapter, negative or absent staff interactions in the wards resulted in participant ill-being, while sustained positive interactions during creative sessions resulted in participant well-being. The preceding sections of this chapter focused on robust and fragile expressions of Self and showed that quality of Self-expression also seemed to be contingent on the types of interaction that participants experienced.

In this section, I will introduce the concepts of *recognised* and *supported Self*, along with their counterparts: *unrecognised* and *unsupported Self*. As mentioned previously, these concepts seem to be crucial elements of interaction in influencing robust or fragile expressions of Self. I will firstly discuss this important finding, using these concepts to deepen our understanding of the relationship between interaction, well-being and Self-expression, before presenting a comparative tabulation of my findings.

Recognised Self

The concept *recognised Self* captures instances in which staff acknowledged or identified with aspects of participants' Self. While being similar to Kitwood's (1997) idea of recognition (as explored in the previous chapter), recognised Self extends on this through its focus on recognising Selfs 1-3 within interaction as opposed to simply recognising the person. My data from the wards suggest that, in their interactions with participants, staff recognised Self 1, but seldom recognised Selfs 2 and 3, as discussed below.

Self 1

As seen in the previous chapter, staff most often addressed participants by name; this being the simplest form of recognition. For example, from ward 1:

> *The student nurse says: 'Bye, bye, Nora'.*

And in ward 2:

> *A care assistant comes into the ward at the start of her afternoon shift. She greets the women in turn and gives Hannah a warm greeting: "Hello, Hannah". Hannah responds by gesticulating and chuckling.*

In ward 2, Nina, the trainee OT was particularly skilled at recognising and responding to Hannah's distress. One day, when Hannah had spent 20 minutes in ill-being:

Nina spots Hannah sitting rocking by herself. She goes to her and calls her name. Hannah immediately responds by sitting up and smiling at her. They have a little chat and reminisce together and Hannah smiles and gesticulates with her hands. Her well-being rises.

Here, Nina recognised and sympathised with Hannah's anxiety, therefore recognising, at a deeper level, Hannah's Self 1.

In ward 3, where care was time and task-oriented and carried out as quickly as possible, staffs' recognition of Self 1 was limited to calling the men by name and those, like Charlie, Paul and Kevin, with the most cognitive or mobility difficulties were the most isolated. For them, simple acts of recognition were often crucial in preventing their well-being from dropping further. In this extract from my DCM notes, Charlie had walked in isolation and sometimes in ill-being for 35 minutes. The cleaner's kind words of recognition were enough to raise a smile from Charlie; briefly alleviating his isolation:

Charlie has walked up to the front door… The cleaner is about to leave. She catches up with Charlie and looks at him, to explain to him that she needs to get out. Then: 'Oh, you're a wee soul' she says kindly. Charlie smiles at her.

Self 2

While ward staff generally recognised Self 1, there was much less recognition of Self 2. What recognition there was, often revolved around present physical characteristics as opposed to past achievements or abilities. For example, from ward 1:

> *Nora has a lovely interaction with a student nurse and her neighbour when they compare the warmth of their hands. There is lots of engagement and smiling.*

And in ward 3:

> *William returns to the sitting room and engages in a warm conversation with the agency care assistant and some of the other men in which they compare their hair and eye colour.*

In ward 2, I observed one particularly warm occasion, when a care assistant recognised Hannah's valued Self 2 attribute; her painting ability:

> *'You like colours, Hannah'. Hannah nods and smiles. 'Hannah's a great painter' she says and Hannah nods and smiles. The care assistant tells me that Hannah has drawn some great pictures of the staff… Hannah continues to nod and smile and gesticulate with her hands.*

Apart from Michael, the art therapist in ward 1, the OT staff were more likely to recognise participants' Self 2 attributes; often resulting in increased well-being. Every time that OT staff approached participants inviting them to take part in the creative sessions, they recognised Self 2; present or potential abilities. Mary

particularly responded to interactions by OT staff in which they recognised her as being capable; as having a valued Self 2:

> *Mary spends the next 15 minutes trying to get up from her chair; slipping in and out of ill-being. Then Karen (OT) comes in to set up the creative session; she goes over to ask Mary if she would like to take part. Mary immediately brightens up and says that she would.*

Here, from my fieldnotes during another creative session in ward 2 is a powerful example of recognising Self 2 and its impact on well-being:

> *Nina says: 'You're as good a painter as every one said you were!' Hannah, smiles, gesticulates and reaches over to stroke Nina's hair, her eyes widen with pleasure and they both engage warmly.*

In ward 3, where ward staff seldom recognised participants' abilities and achievements (past or present), the weekly creative session became a place of celebration as OT staff praised participants' work; recognising and engaging with their present Self 2 achievements:

> *Bill … is pleased and proud with the finished result. He takes out his harmonica to give us a tune: 'A celebratory tune!' says Michael.*

Self 3

There was little recognition of Self 3 in the wards, apart from the occasion noted previously, when the care assistant in ward 2 referred to Hannah's painter persona:

> *'Hannah's a great painter'.*

During creative sessions in ward 3, OT staff often conversed with William and John about their enthusiasm for golf; recognising their Self 3. One day, during a particularly bright session, John responded to Mary's (OT) recognition of his working-man persona:

His eyes are bright and he sometimes gives Mary a fleeting smile. Mary asks him; 'John, what did you do for a living?' and John replies: 'Oh, I had several jobs'.

In ward 3, Eddie (OT) and the minister who sat and chatted with Bill and William and took an interest in their life stories, were the only people outside of creative sessions to recognise Self 3.

Unrecognised Self

This concept captures instances where staff did not recognise Self, evidenced by abusive behaviours, invalidation, withholding or failure to acknowledge participants' subjective experiences. There were no instances when OT staff failed to recognise participants' Self during their interactions with them. However, my fieldnotes have many entries, which seem to indicate that ward staff did not fully recognise their patients' selfhoods. For example, from ward 2:

The staff are in the big sitting room chatting together. Someone is rattling persistently on the front door, another is calling loudly and someone else is sobbing. Hannah has been left sitting in the little sitting room and is now sitting in isolation.

And from ward 3:

The ward is quiet; men are sitting, sleeping or walking. Staff are watching

television.

There were also occasions, when staff did not seem to recognise individual aspects of Self, as discussed below.

Self 1

In ward 1, I saw clear evidence of an unrecognised Self 1 when staff interacted with Florence roughly. Her grief and indignation suggest a Self in ill-being. Here, from my fieldnotes is an occasion when staff took Florence to the toilet:

Hardly had the toilet door closed when I heard Florence shouting and

then the care assistant shouting back. Two other staff move quickly to

the bathroom and it becomes suddenly noisy; loud voices and

underneath, the sound of Florence wailing. Suddenly the bathroom door

opens and out comes the care assistant, backwards, with Florence

facing her and pushing her with her arms outstretched. The care

assistant is half laughing, half cross, but Florence is distressed: 'Oh me

me'. Two staff manoeuvre Florence further down the corridor and leave

her there sobbing: 'Oh me me, oh me me'.

Hannah's distress in ward 2 was often unrecognised and unacknowledged by ward staff. Here, from my DCM notes is one episode of unattended distress:

She slips back into ill-being for a further 15 minutes. There is a care

assistant and a staff nurse in the sitting room but they don't seem to

notice. At this stage, I intervene and abandon the map. I go to talk to

Hannah who is now distressed: whimpering, looking very anxious,

rocking back and forth…

These two examples of an unrecognised Self 1; containing elements of malignant social psychology are abusive and neglectful respectively. However, they also seem to show a complete lack of recognition of Florence and Hannah as sentient individuals.

Self 2

In all the wards, staff most often did not recognise present Self 2; participants' remaining abilities. As discussed in the previous chapter, there are many references in my fieldnotes and DCM notes to outpacing, objectification and disempowerment; in which staff interacted with participants in ways which denied them independence of action. For example, from ward 2:

A care assistant takes Kate to the toilet. She pulls her along towards the

bathroom.

And, from ward 3:

A care assistant pulls Paul up from his chair, and pulls him out to the

toilet.

Frequently, the generalised nature of staff interactions meant that staff did not distinguish between participants' differing abilities (Self 2). For example from ward 3:

A care assistant hands out mugs of tea and chocolate biscuits. The

biscuits are wrapped in foil and the care assistant unwraps the biscuits

before handing them out. She does this for Bill and William who would be well able to unwrap it themselves.

Self 3

Self 3 seemed to be the least recognised aspect of Self in all the wards. In ward 1, Florence was Brethren and her standards of behaviour, for herself and for others, would have been high. One part-time member of staff occasionally acknowledged her Brethren persona, but for most of her everyday life, there was little opportunity for expression of this important aspect of herself. Florence's frequent aggressive outbursts could be interpreted as reflecting her indignity at how her persona was so often unrecognised. This most often led to increased isolation and ill-being as staff failed to recognise the source of her aggression and as they malignantly positioned her as aggressive.

In ward 3, John's limited attempts to occupy himself (Self 3) most often went unrecognised by the ward staff. Here, from my DCM notes:

> *When I arrived on the ward, John was standing in the corridor facing the wall and running his fingers along it, as if drawing. When I start the map ¾ of an hour later, he is still here, running his fingers over and over on a small stretch of wall. He spends 25 more minutes doing this.*

In both of these extracts, participants remained in isolation, as ward staff failed to recognise different aspects of Self 3.

Supported Self

This concept refers to occasions when staff interacted in ways, which affirmed or bolstered aspects of participants' Self. Occasionally, ward staff supported Self. However, most of the supportive interactions occurred during the creative sessions, as discussed previously.

Self 1

On one occasion, in ward 2, a care assistant successfully supported Mary's Self 1. Mary, being relaxed and alert was able to respond positively and her well-being rose.

> *The care assistant finds an envelope on the floor with Mary's name on it and she gives it to her. She squats down beside her and looks at the letter with her and admires the picture on the card.*

On another occasion, when Isabel had refused to accompany a care assistant to the dining room for lunch, another care assistant worked to support Isabel as a unique being with a resultant rise in Isabel's well-being:

> *Shortly afterwards another care assistant persuades Isabel to come with her. Isabel and the care assistant go together into the dining room, they have a banter as they go and Isabel brightens and smiles.*

In ward 3, I saw one rare occasion when a care assistant reminisced with Charlie, thus supporting Self 1. Here, from my fieldnotes:

> *I spot S chatting with Charlie. I sidle round and squat down nearby. Charlie is talking about his cat and S is encouraging him.*

Self 2

Self 2 was most often supported during creative sessions. In ward 2, although Hannah's condition had deteriorated following a bad fall, she still managed to paint and to express Self 2 with support from Eddie:

> *She is so fragile, but she still manages to paint on the silk and to smile, gesticulate and mime like the old Hannah; although with less vigour than usual. When she starts to paint, she does so with lots of support and encouragement from Eddie. Occasionally she becomes worried, but Eddie steps in to reassure her. She relaxes and engages with Eddie and smiles.*

Another time, in ward 2, Eddie supported Mary to the extent that she was able to take control over her painting; resulting in increased well-being and expression of her humorous Self 2 :

> *Eddie offers Mary lots of help…There are some hesitant times, lots of concentration and guidance but also some times when Mary takes the initiative and decides for herself what to do. There is much laughter and Mary's sense of humour begins to emerge.*

A few times, in ward 3, student nurses or agency staff supported Self 2 (remaining ability) by playing card or board games with the men. For example:

> *A student nurse comes into the sitting room with a pack of cards to play with William and they manage a game of rummy.*

However, regular ward staff did not support Self 2.

Self 3

In ward 1, I observed an occasion when a care assistant supported Nora's and another woman's Self 3, when she asked them if they would like to help with the laundry. Here, from my fieldnotes:

> *They agree and join her at the trolley; piled high with sheets and towels. They go to the laundry cupboard to help stack the shelves. Then they leave the ward with a folded cardboard box each for uplift. They return animated, with eyes shining. They remain in this state of well-being for the next ten minutes while they continue to help. When they return to their chairs, they talk with each other about the work they have done.*

Here, for a short while, the women were supported in carrying out familiar domestic tasks: tidying laundry and putting out rubbish. Their animation and their continued talk with each other when they returned indicate that, for a short time, they had taken on and enjoyed the once familiar role of homemaker (Self 3 persona).

In ward 2, when the staff nurse supported Edward's need for occupation as mentioned in the previous chapter, she also supported Self 3: his working-man persona:

> *She calls over to Edward to come for lunch, 'no, no' he replies. 'Oh come on, Edward'. 'No'. Then she asks him to help her push the drugs trolley up to the dining room. Up he jumps and, making his funny face he starts to push the trolley towards the dining room. He pushes it all the way up*

and positions it where the nurse indicates. 'There, there' he says, smiling.

During the creative sessions, it was Hannah's Self 3 (artist persona) which emerged most strongly; again with support from OT staff. Here, from my fieldnotes:

I noticed something today: Hannah draws and paints with such conviction and assurance. She is not like this at all in her every day life in the ward. She can get very anxious, jittery, wriggly, distressed, but during her time at the session she concentrated, looked at Eddie, sized him up to draw him and drew with confidence.

In the conversations we had, while watching downloaded footage of their participation in creative sessions, Bill and William stated their desire for occupation and that the creative sessions fulfilled this need. In this sense, the creative sessions supported their need to express working-men personae. Bill's conversation was erratic, but he did state several times that he liked the sessions because they:

'…keep your mind occupied…you just think whatever comes into your head and you write down accordingly.'

William suggested that:

'If you have something nice to draw, it's lovely drawing.'

Unsupported Self

This concept captures occasions when participants tried to express aspects of Self, but staff did not act on Self-expression. As with unrecognised Self, in the wards there were many occasions when staff did not support Self. For example, from ward 1, following a trip out to the garden:

> *The door opens. Four men and women and two staff enter, they get half way down the corridor and the staff wander off to speak to the other staff who are sitting watching TV. All four are abandoned and unsettled. So what do they do? Turn round to the door, try it: it's locked. Two others join them and now there are six men and women at the door rattling the handle trying to get out. The staff are watching TV. The six are becoming increasingly frustrated. Edward particularly so. He rattles the handle and bangs on the glass, over and over. Up and down the corridor he goes, with a trail of men and women behind him, looking for a way out.*

Here, by not escorting their patients to their chairs, ward staff failed to recognise their selfhoods. As they did not recognise their mounting frustration, they could not support their patients by providing them with occupation or interaction; contributing to their increasing restlessness and ill-being.

In ward 1, Michael failed to support Self 2 and this resulted in unsatisfactory experiences for Edward and Florence, as discussed below.

Self 1

While ward staff often recognised Self 1, they often did not go that bit further in their interactions to support it. For example, from ward 2:

Hannah has slipped into ill-being… she has her head in her hands; is bent over and wriggling. She remains in ill-being for over 10 minutes. A staff nurse passes by and notices her bent over position: 'are you alright in there?' she asks. Hannah immediately lifts her head up and looks around, a smile on her face, but the nurse is gone…

And from ward 3:

A care assistant passes John and says: 'You alright, John?' John responds to her disappearing back: 'Aye'.

And:

Charlie is up again; walking… He approaches the staff nurse. Charlie reaches out and the staff nurse asks him what he wants. Charlie's speech is difficult to make out and the staff nurse says: 'if I can help you, I will', but he's still walking. Charlie follows him for a few steps; hand outstretched, but the nurse is too quick and he's away.

In these extracts, ward staff recognised Self 1; by referencing participants as *"you"* or addressing them by name, but by not waiting long enough for a response or, as in Charlie's case, by withholding his need for contact, they failed to support Self 1.

Self 2

In ward 1, during the creative sessions, Michael failed to support Edward's and Florence's Self 2; he failed to engage with them enthusiastically or encouragingly in order to maximize the possibility that they might reclaim a past

Self 2 attribute. This meant that their times at the creative sessions were unsatisfactory.

Edward does little in the creative session. Occasionally Michael stands over him, asking him how he's doing, but Edward doesn't engage with Michael and Michael doesn't work to engage with him.

And:

Now Florence has lost interest in painting and she sits looking vaguely around her and vaguely at the brush in her hand. Michael goes to her and briefly encourages her to paint, but Florence responds with: 'it's a load of rubbish'. Shortly afterwards she removes her apron, and stands up...

These examples show that even those trained to a high standard do not automatically acquire the skill required to interact meaningfully and supportively with people with dementia. They also highlight the need to support those who try to care for people with dementia in a person-centred way.

In ward 2, Mary often attempted to stand up; to exercise her Self 2 attribute of independence of action. While staff sometimes recognised this, they failed to support her:

Mary decides that she wants to stand up… she is pushing herself up using her hands and is weight-bearing while holding on to the arms of her chair. She tries over and over to stand up but does not fully succeed. She is becoming anxious and frustrated. On two occasions during the

next 10 minutes she asks passing care assistants for help but is told both times that they cannot help, that she can't walk and that she is to sit down.

Had the ward staff helped her to stand for a short while, rather than telling her that she was unable to walk, they would have supported her Self 2: her desire to reclaim some sense of independent action.

At other times, because ward staff did not recognise attempts to express Self 2, particularly attempts to reclaim a past ability, they were unable to offer the support required for its successful expression. For example:

Kate is trying to drink from a beaker, but the staff do not notice that she is holding it the wrong way so she spills most of it down her front. She does not manage to drink any of it.

In ward 3, of the many instances of unsupported Self 2, the following episode was the most prolonged. Here, ward staff who were present in the room, consistently ignored and therefore did not support Paul's attempts to drink from a plastic beaker:

He manages to drink his coffee for 25 minutes… He continues to put the beaker to his mouth trying to take sips from it… He is no longer managing to drink, not able to tip the beaker high enough. He remains like this for the next 75 minutes.

Self 3

Because it seemed that ward staff seldom recognised Self 3, it follows that they often could not support this aspect of participants' selfhoods, often resulting in participant ill-being.

In ward 1, when Nora tried to enact Self 3 (a domestic persona), staff did not recognise or support her efforts, resulting in ill-being:

> *Nora is served her soup but she is unhappy with the soupspoon. She stands up to go to clean it but is intercepted by the staff nurse who takes it from her, looks at it and explains that it only has soup on it. The nurse then puts the spoon into the bowl and brusquely tells Nora to sit down. Nora refuses to eat her soup. She slips into ill-being.*

Had the nurse allowed Nora to wash her spoon, or choose another one, she would have supported her wish to take control over an unsatisfactory situation and co-constructed with Nora her desired role of home-maker. Instead, by disempowering her; by not supporting her in her desired role, the nurse contributed to Nora's increasing ill-being.

Another time, staff invalidated Nora's desired role as wife, which caused her distress. Here, from my fieldnotes is an episode in which she was unsupported in fulfilling her desired role:

> *She is now unsettled and out of sorts. She starts looking for the key to get out in order to 'make my man's tea'. She is becoming agitated, as her repeated attempts to find someone with a key are unsuccessful… Nora*

asks the staff nurse for the key, he shows her his one, her face lights up but he puts it back in his pocket. Her face falls and she looks puzzled. He talks conspiratorially in her ear 'don't tell anyone, I'll let you out later'. And away he goes.

In ward 3, when John did manage to occupy himself (Self 3), ward staff also thwarted his efforts. One day, after a creative session, he found a staff folder:

He stands, intently looking through it and turning over the pages. Then a care assistant comes in and I hear her scolding him: 'Oh, John!' I hear his voice; cross, protesting. She has taken the folder from him.

Had the care assistant replaced the folder with a book, she would have supported his need for occupation. Instead, her actions caused him ill-being.

Near the end of my time in ward 3, I sat in the sitting room and tried to see the men from a position of 'not knowing' and I sensed how easy it would be to assume that there is no selfhood. Here, from my fieldnotes is my observation of how staff might perceive Paul and Kevin and of how such perceptions might dictate whether or not they might interact with them in ways that recognise and support Self:

These men can be on their own for hours without interaction and, if viewed with an outsider perspective, they appear blank. They sit where they have been put, they occasionally look around them, Paul rocks and bends down to lick the table or sits with his long tongue stretching down to his chin. Kevin blinks slowly and sits. They do not initiate interaction.

They sleep. The only interaction they receive from the staff is when they are being fed or taken to the toilet… It seems that, because the staff do not interact with the men in meaningful and affirmative ways, they do not recognise their selfhoods and if they do not recognise selfhood, they cannot interact with them as having Self and so Self is not sustained by them. If there are no opportunities for Self-expression and if communicative or cognitive resources are damaged, then it is probably inevitable that a person will slip into blankness, and so will be perceived as being blank. And so a negative spiral ensues.

Yet, in my interactions with and observations of them, Paul and Kevin clearly expressed Self, albeit in subtle, fleeting ways. What was lacking was not their selfhoods, but staffs' recognition and support of their selfhoods.

Quantification of findings

As discussed in chapter 4, I followed the hunch that recognising and supporting Self might be an important part of interaction in influencing well-being. I searched the data (fieldnotes, DCMs and video-footage) and identified instances when ward and OT staff recognised and supported Self and instances when they did not recognise or support Self. I counted each instance and separated them according to which aspect of Self was recognised, unrecognised, supported and unsupported, and by whom. Table 4, below, gives the tabulation of the comparative analysis.

Table 4. Number of interactions by ward and OT staff in which Selfs 1-3 were recognised, unrecognised, supported and unsupported.

Recognised Self

Ward	S1	S2	S3	Creative sessions	S1	S2	S3	
1	9	4	0		1	1	0	
2	42	7	0		31	22	0	
3	22	2	3		29	8	6	**Others:** 5 2 1

Unrecognised Self

Ward	S1	S2	S3	Creative sessions	S1	S2	S3
1	14	11	11		0	3	0
2	49	26	15		0	0	0
3	51	51	33		0	0	0

Supported Self

Ward	S1	S2	S3	Creative sessions	S1	S2	S3	
1	2	0	3		2	1	0	
2	2	1	0		12	29	9	
3	5	6	0		3	8	2	**Others:** 2 1 0

Unsupported Self

Ward	S1	S2	S3	Creative sessions	S1	S2	S3
1	7	11	11		1	3	0
2	12	17	14		0	0	0
3	19	20	21		0	0	0

Table 4 supports the qualitative findings discussed above; that ward staff were less likely than OT staff to recognise or support participants' Selfs 1-3. As seen in this quantification, while ward staff more often recognised Self 1, they were less likely to recognise Self 2 and seldom recognised Self 3. There are many instances when they did not recognise or support Self in their interactions, with staff in ward 3 less likely than staff in wards 1 and 2 to recognise or support their patients' Selfs. In their interactions during creative sessions, OT staff recognised and supported Self, and with the exception of Michael's interactions, I saw no instances when OT staff failed to recognise or support Self.

Conclusion

In this chapter, I have described participants' verbal and visual expressions of Selfs 1-3. I have shown how each participant expressed Self in unique and individual ways and in ways that were robust or fragile. In the wards, there was

little opportunity for Self-expression for those participants with the most cognitive and communicative difficulty and, owing to predominantly limited recognition and support received by these participants, what Self-expression there was, was often fragile.

Even with cognitive and communication difficulties, participants did express Self when given the opportunity or means to do so; often in their interactions with me and the OT staff. During the creative sessions, in which positive interactions prevailed, participants sometimes showed unexpected proficiency, a fragile expression of Self could become a robust expression of Self, a past Self 2 could be reclaimed and a desired Self 3 could be co-constructed. On these occasions, Self was transformed and well-being increased.

On return to the wards, participants sometimes tried to express that aspect of Self that they had expressed during the creative sessions, although with varying degrees of success. Most often, ward staff did not recognise or support enhanced Self-expression and participants either reached out to me or gave up and withdrew.

I have introduced the concepts of recognised Self and supported Self, along with their counterparts, which I propose are crucial elements of interaction for either nurturing or undermining expression of Selfs 1-3. As shown in Table 4 (page 286), my findings suggest that OT staff generally appeared to recognise and support Self in their interactions during creative sessions, whereas ward staff did not appear to fully recognise and therefore could not support Self. This

seems to be a fundamental barrier to carrying out authentic person-centred care and may go some way towards explaining the limiting and damaging interactions I observed in the wards.

These findings reflect seriously on the quality of care received by participants in the wards and indicate that transformational change in practice is required. In the final chapter, I will discuss my findings in relation to the research questions, suggest key messages for practitioners, policy makers and academics, which might further improve care and consider some of the strengths and limitations of this study. I will then argue for the central point of this thesis; integrating the selfhood approach into the person-centred approach in order to encourage ways of interacting which would transform practice and, ultimately, enhance well-being of people with dementia. Finally, I consider how the study has contributed to the body of knowledge about dementia and dementia care before suggesting areas for further research.

Chapter 8: A person-centred/selfhood approach to dementia care

Introduction

This was a multi-method ethnographic study, grounded in symbolic interactionism and social constructionism. It was carried out over six months in three long-term wards of a hospital with the aim of answering specific research questions (see pages 15 and 16). Its focus was to observe and categorise types of interactions that participants with dementia experienced in every day ward life and during creative sessions facilitated by occupational therapy staff and the art therapist, and to identify participants' responses to such interactions in terms of their well or ill-being and expressions of Self. Fourteen people with dementia gave ongoing consent for me to observe them in their everyday lives and to carry out Dementia Care Mapping. Six of them gave consent for me to video-record their participation in creative sessions and three to carry out focused conversations to gain insight into their opinions on taking part in the sessions.

My findings suggest that ward staff did not generally work within a person-centred philosophy. While they engaged in some positive interactions, these were most often brief, being time and task-oriented and minimal. Many interactions were limited in their potential for raising participant well-being and some were damaging or abusive, causing participant ill-being. Those participants with the most cognitive or mobility difficulties were the most isolated and at risk of experiencing ill-being. Even with cognitive and communicative

difficulties, participants did express Self in unique verbal and visual ways and in ways which were often fleeting and subtle. Participants often expressed Self in fragile ways, reflecting their ill-being. This was particularly the case for those with the most cognitive and communicative difficulty.

During creative sessions, occupational therapy (OT) staff generally engaged in sustained positive interactions, raising participant well-being. With sustained positive and supportive interaction from OT staff, participants often expressed Self with unexpected proficiency, a fragile expression of Self could become a robust expression of Self, a past Self 2 could be reclaimed and a desired Self 3 could be co-constructed.

Following creative sessions, some participants tried to maintain their well-being and continue to express a robust Self. However, in the absence of recognition or support from ward staff, their attempts were most often unsuccessful.

It seems that while OT staff generally recognised and supported Self of participants in their interactions, ward staff did not fully recognise and therefore could not support Self. This is a crucial finding, reflecting poorly on the quality of long-term nursing care for people with dementia and could partially explain the apparent poverty of person-centred care in the wards and the frequency of damaging interactions that I observed. While I have previously pointed to concerns held by practitioners about the feasibility or practicality of carrying out person-centred care (Packer, 2000b; Innes, 2002; Brooker, 2004), I have also maintained that we must still strive towards a change to person-centred

practice. How can we foster person-centredness if practitioners do not seem to fully recognise selfhood? In this chapter, I will explore the implications for practice of my findings and suggest that practice might be improved by developing a potentially transformative approach to dementia care: integrating Sabat's (2001) selfhood approach into Kitwood's (1997) person-centred philosophy within an innovative staff-training programme.

First, I will revisit the research questions posed in chapter 1 and link the findings with some of the theory and research discussed in the earlier chapters of this thesis, before discussing some of the limitations and strengths of the study. I will then argue for integrating a selfhood approach into the person-centred approach and lay out what I consider to be the key messages for practitioners, policy-makers and academics by which a change in practice might be achieved. I will discuss how this study has contributed to knowledge about dementia and dementia care, before finally suggesting some areas for future research.

Revisiting research questions

In this section, by linking my findings with some of the theory and research discussed in the earlier chapters, I add theoretical context to the findings and add to the body of existing knowledge about dementia and dementia care. I also attempt to tease out some of the underlying reasons for the different types of interactions I observed in the wards and creative sessions. In keeping with the structure of the thesis, I will focus in turn on interactions in wards and interactions during creative sessions in respect of participants' well/ill-being levels and their Self-expression.

Interactions in the wards and well/ill-being

Research questions: what types of interaction occur in the wards, what are participants' well/ill-being levels and what factors influence well/ill-being?

As discussed in chapter 6, while some staff interacted with participants in positive ways; briefly increasing participant well-being, many more interactions were limited in their potential for maintaining or increasing well-being; being time and task-oriented, minimal and carried out as quickly as possible. Ward staff engaged in all elements of malignant social psychology with varying degrees of severity and with sometimes serious decline in participant well-being.

In chapter 1, I discussed how a biomedical understanding of ageing often positions ageing people as in a state of biological decline, rather than as persons with remaining potential. Those with dementia face further biomedical assumptions of cognitive decline and loss. In the wards, it seems probable that dementia was understood in biomedical terms. This seemed to influence staff behaviour, as evidenced by the withholding of emotional comfort, the lack of occupational provision, the time and task-oriented nature of interactions and the reliance on physical and chemical restraints to manage "difficult behaviour". The focus on cognitive impairment as the basis of interaction meant that those, like Florence, Kate, Brenda, Charlie, Paul and Kevin who appeared to be severely cognitively impaired, experienced little meaningful engagement from ward staff, often being treated as "things" rather than as persons (McCormack, 2004). Table 3 (page 209) which shows that Nora, Florence, Brenda, Kate, Charlie and

Paul (non-participants in creative sessions) had unacceptably low average WIB values, is further evidence of the lack of meaningful interaction that they received and its resultant impact on their well-being. This study supports Edelman et al.'s (2004) findings that those who were most cognitively impaired were most at risk of experiencing low quality of life as measured by low WIB values.

My findings suggest the continued existence of the old culture of care in the wards, as described by Kitwood (1997:136), in which care is institutional and regimented, patients' physical needs are cared for at the expense of psycho-social needs and "problem behaviours" are managed, sometimes by drugs or by punitive interactions. It seems that little has changed since Armstrong-Esther et al. (1994) reported on the minimal task-oriented interactions between nursing staff and old, frail institutionalized people. Care remains custodial, as evidenced by the locked wards, there is little emphasis on restorative interactions and patients continue to spend long stretches of time in isolation. Indeed some participants particularly Kate, Brenda Charlie and Paul who had the most cognitive difficulty spent longer in isolation than those in Armstrong-Esther et al.'s (1994) study; 60-80% of their time as opposed to 45%. It seems that nurses still "make strangers of their patients" (Armstrong-Esther et al.,1994:270), particularly those with increasing cognitive difficulty who still live in "deserts of loneliness" (Elias, 1985:74).

My findings also concur with Bury and Holme's (1991) recognition that there is little occupational provision for patients other than the inevitable television.

However, my study extends this idea by describing how ward staff used the television to their advantage; watching it for long periods when their tasks were done and only interacting to intervene when participants became aggressive or when it was time to carry out scheduled tasks.

I suggest that in an institutional environment where work is regimented, focused on order and restricted to performance of physical tasks, adhering to a person-centred approach is extremely difficult without extensive support from the top down and mentoring from the bottom up. Kitwood's ideal of a new culture of care still seems to be some way off, but may be achieved by integrating a selfhood approach into the person-centred approach to care, as I will propose later.

While participants experienced limited and sometimes damaging interactions in the wards, those who attended creative sessions generally experienced sustained positive interactions from OT staff, raising their well-being. The success of OT interactions shows that it is possible to interact meaningfully with people with "severe" dementia and for them to experience such interactions as meaningful, as discussed below.

Interactions in creative sessions and well-being

Research questions: What types of interaction occur during creative sessions, what are participants' well/ill-being levels during creative sessions and what factors influence well/ill-being?

My findings support some of the art therapy literature, discussed in chapter 3. Perhaps the most notable feature of the creative sessions was their capacity to promote well-being, as evidenced by the quantitative and qualitative data in this study. Both McNiff (1994) and Spaniol (2001) talk of the power of creativity to promote well-being; through painting together, meditating collectively on the images and through the communication that the images evoke (McNiff, 1994) and through its social, psychological and formal functions (Spaniol, 2001). As Appendix 12 and Table 3 (page 209) show, all the participants who attended creative sessions experienced increased well-being. Of these participants, Hannah seemed to become most transformed during the sessions; both in the process of painting and in her pleasure with the product. Following Spaniol's analysis, the social function of the creative process ensured that Hannah experienced extended positive interaction, its formal structure allowed her the possibility of conveying meaning through her painting and its psychological function alleviated her anxiety, as seen in her increased WIB values.

Leslie (2001) suggests that the process of creation seemed to be more important than the product, as seen in the atmosphere of calm which descended on participants, while Osler (1988) talks of a reduction in anxiety and an increase in confidence that occurred in a man with Alzheimer's disease when he painted. These points particularly seemed to be the case with Hannah and Mary in ward 2. Both would arrive at creative sessions expressing anxiety, but with encouragement and gentle support their anxiety decreased and their well-being rose, as seen in Table 3 (page 209) and Appendix 12. The reduction in Hannah's anxiety was the most striking. Gone for a short while was the

rocking, whimpering woman I so often observed in the ward; to be replaced with someone whose eyes would widen with pleasure, who would nod, gesticulate and smile and who could take pleasure in once again creating images and sweeps of colour.

Wood (1998) suggests that, by giving people freedom to use art materials in whichever way they wish, they achieve a sense of control. This seemed to be important in ward 3, where participants had little control over their lives or their environment and where many staff interactions were disempowering. Participants expressed control in a number of ways. For example, John took control when he successfully used a pair of scissors to cut out shapes of material. William spontaneously folded a sheet of paper to make an aeroplane, stimulating an animated discussion about Concorde and Bill seemed to order his thoughts in his repeated production of discrete, isolated images. Here, control over both the process and the product seemed to stimulate well-being.

However, 32 years ago, Ulman (1975b) pointed out that the effectiveness of any creative session depends on the quality of life during those other 23 or so hours of the person's day. For most participants, the other 23 hours of that day and the six other days of that week, brought mainly limited and damaging interactions, resulting in fluctuating levels of well/ill-being.

This study has shown that, while the process of creating may have been beneficial for some participants, what seemed to be of most importance in maintaining or increasing their well-being and facilitating Self-expression was

the opportunity for sustained positive interactions that the sessions afforded; in which Self was recognised and supported. What this study also reveals, is the poverty of sustained positive interaction received by those who did not attend creative sessions, and it was this group who had consistently lower WIB values (Table 3, page 209 and Appendix 12).

I cannot determine whether this group of participants might have experienced increased well-being and enhanced Self-expression during creative sessions. However, in their interactions with me, their well-being often increased and they sometimes expressed Self in profound and unexpected ways, indicating their retained capacity for well-being and Self-expression, and suggesting that negative staff interactions in the wards played a part in these participants' experiences of ill-being and their fragile expressions of Self.

Interactions in wards and Self-expression

Research question: How do participants express Self in the wards and what factors influence Self-expression?

In chapter 7, I showed how participants did express Self verbally and visually in the wards when given the opportunity or means to do so, particularly in their interactions with me. However, often their expressions of Self were fragile, which I defined as negative expressions of Self in the context of ill-being.

Life within an institution seemed to have a huge impact on participants' Self-expression. Gubrium and Holstein (1999) described the nursing home as being a discursive anchor for the ageing body. An institution, such as Moorhills

Hospital is perhaps more constraining; for here, the ageing body was also categorised as being "demented". In Moorhills, the ageing, "demented" body was observed, monitored, catalogued, evaluated, restrained, regimented, ignored, objectified and labelled. Within such constraints, there was little opportunity for Self-expression, particularly for those with the most cognitive and communicative difficulties.

From a social constructionist position, as described in chapter 2, Laing (1961) proposed that others' confirmation or disconfirmation influences sense of self. Even the slightest sign of recognition from another person confirms one's existence in that person's world, while disconfirmation denies that person his/her existence in the other's world. Without recognition of one's existence by others, one is placed in an increasingly vulnerable position; existentially impacting on self and well-being. With increasing cognitive decline and decreasing psychological reserves, self becomes increasingly vulnerable, requiring intense confirmation in order to sustain self. As ward staff seldom fully recognised or supported Selfs 1-3, thus disconfirming Self and denying participants sufficient existence in the wards, this may have contributed to the fragile expressions of Self and attendant ill-being that I observed in the wards.

The symbolic interactionist and social constructionist ideas on labelling and positioning are useful in explaining why some ward staff behaved as they did towards participants. Positioning of participants in relation to their cognitive difficulties meant that participants often experienced dehumanising and demeaning interactions from ward staff. For example, when the care assistant

reprimanded William for trying to kiss me goodbye, she malignantly positioned (Sabat, 2005) him as deviant (Goffman, 1961) rather than seeing him as a person with normal needs for attachment and warmth (Kitwood, 1997) and as attempting to present a social persona (a social Self 3).

The symbolic interactionist position, which stresses the circularity of interaction and attribution may also help to understand why ward staff malignantly positioned William when he tried to express Self, or why they failed to notice the meaning of Brenda's or Charlie's isolated walking or Kate's attempts to pull other women from their chairs in the evening. Blumer's (1969) three lines of meaning, which I discussed in chapter 2, may be a useful starting point. When confusion or misunderstanding occurs along any one of Blumer's lines of meaning, communication will be ineffective, interaction will be impeded and joint interaction will fail. It seems that, because ward staff did not fully recognise participants' Self-expression, whether it be robust or fragile, they misinterpreted or misunderstood its significance. Without recognition, there was little chance of supportive interaction, thus, positive, confirming or remedial interaction was either unsuccessful or did not occur and participants continued to experience ill-being.

We also "take the role of the other" (Mead, 1934) in order to define others' intentions and actions and to determine how we will act on such intentions and actions (Charon, 2007). By failing to "take the role of the other", staff failed to find meaning in participants' actions and interactions. Thus, William's goodbye kiss to me was misinterpreted as deviant, based on staffs' previous

expectations of his behaviour stemming from his initial hospitalization, rather than on his apparent non-sexual attempt to say goodbye. In failing to find meaning in Brenda's and Charlie's constant walking, staff attributed their actions to their dementia rather than as fragile expressions of Self resulting from the disconfirmation they experienced in the wards and in failing to understand that Kate sought social contact, they ignored her when she tried to pull other women from their chairs rather than offer her some company.

The social constructionist position, which stresses the positioning of others through language, might also help in understanding why those with the most cognitive and communicative difficulties were the most isolated. In accounting for ourselves, we must meet the demands placed on us by our status as responsible members of society; we must talk in ways that are intelligible and legitimate in the eyes of others. If we do not meet these demands we will be sanctioned and treated as socially incompetent (Shotter, 1985). Language, being more than a symbol for communicating information and intent, is also formative (Shotter, 1989), contributing to the construction of self. Those, like Kate, Brenda and Paul who have no verbal communication, were positioned as having nothing useful to communicate, thus legitimating to staff their minimal interactions with them.

It is beyond the scope of this thesis to explain why ward staff did not fully recognise Self. However, I will suggest some possible contributing factors.

The disengagement theory of Cumming and Henry (1961), which I discussed in chapter 1, viewed older people's withdrawal from society as a natural process of ageing. From this perspective, experiences such as powerlessness, dependency, loneliness and loss of purpose, role and status are natural phenomena of ageing. As these negative understandings of ageing instil fear in those who do not wish to acknowledge their own inevitable decline and eventual death (Kitwood, 1997; Hurd, 1999), it might be easier for staff to distance themselves from such possibilities, thereby distancing themselves from and dehumanising those they fear. Sweeting and Gilhooly's (1997) findings; that some relatives detached emotionally from their loved ones with dementia, behaving towards them as if they were socially dead, add weight to the idea that not recognising Self of participants might be an unconscious defence mechanism against staffs' own fear of cognitive decline and its implications for quality of life.

A further explanation for not recognising Self could lie in the deeply rooted Cartesian understanding of self and, consequentially, the deficit model of conceptualising dementia, as discussed in chapter 3. If care staff presume a loss of self as dementia progresses, it would follow that they will not consider looking for self and will therefore not recognise Self-expression, and so a negative spiral of interaction ensues.

These tentative explanations for why ward staff did not fully recognise Self of participants, and for why participants expressed Self in fragile ways, point, not only to the pervasiveness of deeply held assumptions and understandings of

ageing and selfhood in dementia, but to the need for consciousness-raising (Neel, 2002) amongst staff in order to promote a shift in understanding of selfhood and a change in practice.

Interactions in creative sessions and Self-expression

Research question: How do participants express Self during creative sessions and what factors influence Self-expression?

During creative sessions, OT staff interacted with participants in ways which transformed fragile expressions of Self to robust expressions of Self. Why was there such a marked difference in how OT staff interacted with participants? Again, I can only offer tentative explanations.

The OT staff seemed to work with predominant assumptions of potential rather than loss and this seems to be a fundamental difference between the interactions of both groups of staff. The many supportive actions, such as turn-taking and scaffolding that I observed seemed to reflect their desire to maximise participants' remaining abilities. Here, they worked to enable participants to reclaim valued Self 2 attributes and they positioned participants according to what they could accomplish rather than according to what they had lost (Greene Stewart, 2002). Thus, they implicitly recognised and supported Self.

Participants' responses, in terms of a reclaimed Self 2 or co-constructed Self 3, were often in striking contrast to their passive or anxious demeanour in the wards. This might be understood in relation to learned helplessness theory (Seligman, 1975), which I discussed in chapter 1. Faulkner (2001) found that

learned helplessness in older hospitalized people, resulting from disempowering care, could be alleviated by inducing learned mastery through empowering care. While his participants had no cognitive difficulties, these findings seem to resonate with my participants' responses to their experiences of interaction types. Disempowering interactions from ward staff resulted in participant dependency and attendant ill-being, while empowering interactions from OT staff resulted in increasing self-confidence and attendant well-being. Framing interaction types in terms of how they induce or alleviate dependence is a further signifier of the polarity of interaction carried out by ward and OT staff, with a resultant polarity of response in terms of participant dependence or independence, and ultimately on their well-being and Self-expression.

As learned helplessness and learned mastery can generalise beyond the specific induction, this could also explain why some participants tried to retain their renewed independence and self-confidence beyond the creative setting, as discussed in chapters 6 and 7. However, because ward staff did not fully recognise or support enhanced Self-expression, learned mastery was not reinforced or sustained and participants either withdrew or reached out to me.

Summary

In this section, I have linked some of my findings with symbolic interactionism and social constructionism and with previously discussed research. I have offered some tentative explanations for the types of interactions that I observed in the wards and during creative sessions, and some tentative explanations for participants' responses to such interactions in terms of their well/ill-being and Self-expression. This section, pointing to the complexity of social interactions in

influencing well-being and Self, and to the often embedded and unreflexive manner in which we interact, highlights the huge task ahead of us to change the culture of dementia care.

Limitations of the study

This was a small study; involving only 14 participants with dementia in three long-term wards of a hospital. For this reason, the study is limited in its generalizability to those with dementia in other institutional settings. However, I can claim theoretical generalizability (Mason, 2002) as I have built and extended on existing theory and research into dementia and dementia care. Thus, I have widened the scope of this study and have contributed to a deeper understanding of how interaction types influence well-being and Self-expression. I can also claim theoretical generalizability by widening the resonance of this study in order to ask questions about the types of interactions experienced by people with dementia in other institutional long-term care settings. There are clear, if depressing, lessons from this study; reflecting poorly on nursing practice, which undoubtedly resonate with some other settings.

A possible criticism of this study is that, as I approached fieldwork and participants with the assumption that Self persists even with increasing cognitive decline, it could follow that I would find Self-expression. The converse is also possible: if I assumed that Self does not persist, would this mean that I would have found no expressions of Self? Could I have interpreted some of the verbal and visual expressions as something other than expressions of Self? When I sat and observed Paul and Kevin from a position of "not knowing", as described in chapter 7, I realised how easy it would be to assume loss of Self,

but when I engaged searchingly and meaningfully with them and my other participants, I am in no doubt that their expressions to me, revealed Self. I respond to this potential criticism by stating that it was through rigorous analysis and continuous reflexivity that I identified participants' sometimes clear and sometimes subtle expressions of an enduring selfhood.

I have discussed a further possible limitation of the study in chapter 4, in relation to the reliability of my DCM coding, and have discussed how I resolved such difficulties by adhering strictly to operational rules, by seeking advice from one of my supervisors who is a DCM trainer and by changing codes if they later seemed inappropriate.

Strengths of the study

One of the strengths of this study lies in the fact that I used an ethnographic methodology to explore participants' social worlds. Taking an ethnographic approach to data-collection gave me time to get to know my participants and gave them time to get to know me. This was important when I sought consent from them to carry out DCMs and video-recordings. It also allowed me to "take the role of the other" in order to develop an empathic approach to data-collection and analysis, in which I gained as deep an understanding as I could of participants' experiences of interactions in their everyday lives and in creative sessions, and how such interactions influenced their well-being and Self-expression.

Taking a multi-method approach to data-collection meant that I could gather different types of data: observational, conversational, video, qualitative and

quantitative DCM data and reflexive data from fieldnotes. This was particularly useful in capturing expressions and interactions that another method might have missed. For example, video-recordings captured subtle visual expressions that I might have missed using DCM alone, whereas DCM allowed me to quantify well/ill-being systematically, which observation alone would have failed to do. Fieldnotes allowed me to reflect on the transactional nature of the research, on how I influenced the research and how it influenced me, as I have discussed in chapter 5.

A further strength of this study is that it links Kitwood's (1997) person-centred approach with Sabat's (2001) selfhood approach. Thus, the study illustrates operational elements of interaction and well/ill-being as well as operational elements of Self-expression, and highlights the transactional nature of interactions in influencing well-being and Self-expression. This allows for a more comprehensive understanding of what it is like to live with dementia in institutional long-term care.

Integrating a selfhood approach into the person-centred approach also has strong practical appeal, and it is to this central point that I now turn.

Person-centred/selfhood care

Throughout this study, I have continued to work as a nurse, caring for people with advanced dementia and have continuously reflected on my changing practice; changing in response to my developing thinking about selfhood. Having started from a person-centred perspective, my practice, now informed by symbolic interactionism and social constructionism, has moved towards a

selfhood approach, in which I seek for and respond to expressions of Self of the men and women in my care, and in which I recognise the transactional nature of interactions in nurturing or damaging well-being and Self. This, as a practitioner, has become an enrichingly powerful way to carry out care and, in response to my findings, has become the main thesis of this study, for which I now argue.

One of the features of working within a person-centred approach is that one constantly examines one's own behaviour, watching for elements of malignant social psychology and trying to incorporate elements of positive person work into one's interactions. While it is important to remain conscious of one's practice, this can also result in an element of self-blame and recrimination, which can be particularly distressing for practitioners who are new to person-centred care and who may be shocked at their practice. Without mentoring and support, it may be just too difficult to accommodate feelings of guilt, while striving to change one's practice.

I propose a shift in focus, from examining elements of one's interaction for malignant social psychology and positive person work, to looking outwards towards those for whom we care. I propose integrating the Selfs 1-3 framework into the person-centred approach in order to offer a more holistic, mutually reinforcing way of understanding and caring for people with dementia. If practitioners are taught to look for verbal and visual expressions of Self, this could promote a new way of viewing and engaging with people with dementia. It might encourage ward staff to view their patients as purposeful, sentient people and encourage them to reach out, recognise and respond to aspects of Self as

they carry out care, fostering more meaningful interactions between ward staff and their patients and ultimately improving patient well-being.

In order to develop my argument for integrating the selfhood and person-centred approaches, I will draw on my research findings and focus on the transactional repercussions of either recognising and supporting Self or not recognising and supporting Self; using Self 2 as an illustration. This argument can be applied to all aspects of Self in a similar way.

As I have shown, in their interactions with participants during creative sessions, OT staff were particularly skilled at recognising participants' Self 2; their past, present and potential abilities. For example, as described in chapter 7, when they approached participants and invited them to the creative sessions, they recognised their potential creative abilities. They were also skilled at supporting expressions of Self 2. For example, when Michael supported Isabel in knitting, he supported a past Self 2. On receipt of such support, Isabel showed unexpected proficiency as her knitting skills returned and she began to knit with increasingly less direction from Michael. When OT staff encouraged Hannah to paint, she blossomed as she once again used her painting skills (expressing her past and present Self 2) and as she co-constructed with them her artist persona (her Self 3). It would follow that as OT staff recognised and supported Self, they also interacted in ways which sustained Self; their interactions were facilitatory and celebratory. This raised participants' well-being, as seen in the emergence of humour, increasing self-confidence and expressions of pleasure and pride, which in turn prompted reciprocal positive interactions from OT staff. This way

of viewing and interacting with people with dementia has the potential to fuel a transactional flow of positive interactions.

In contrast, ward staff seemed to less often recognise and seldom supported Self 2. For example, as seen in the previous two chapters, they disempowered participants by pulling them along by their hands instead of allowing them to walk at their own paces, they often did tasks for participants which they would have been able to do themselves and, as they often did not notice when participants required help, they did not offer supportive care. This often caused distress to participants, resulting in deteriorating WIB values. It would then follow that as ward staff did not generally seem to recognise or support Self, they could not necessarily interact in ways which sustained Self, thus they interacted in limited and sometimes damaging ways, often resulting in participant isolation and ill-being, which in turn prompted further limited interactions from ward staff. This way of viewing and interacting with people with dementia has the potential to fuel a transactional flow of negative interactions. I do not wish to be judgemental of the ward staff for their interactions, but point instead to how one can become locked into negative ways of interacting with negative implications for all parties within the interaction, as illustrated in the previous two chapters.

Although my findings strongly indicate this, I cannot claim with certainty that recognising and supporting Self leads to more positive interactions, and that not fully recognising and supporting Self leads to more negative interactions. It might also be that engaging in positive interactions enables one to recognise

and support Self, and engaging in negative interactions blocks recognition of Self. I can however refer to my own developing practice in suggesting that the former direction may be a more fruitful one to take in starting to change practice.

Strategy for introducing person-centred/selfhood care

A staff-training programme which integrates a selfhood approach into the already established person-centred approach could promote more positive staff interactions and facilitate a move towards more person-centred care. This would require ongoing in-the-field staff training, support and mentoring along with evaluation to monitor its influence on practice. But it could be a first step in changing the culture of care that I observed in the three wards, and improving dementia care as a whole.

I propose developing an innovative staff training programme, containing an accessible account of the Selfs 1-3 framework and giving examples of verbal, visual, robust and fragile expressions of Selfs 1-3. I would include the concepts of recognised, unrecognised, supported and unsupported Self, giving examples of practice which demonstrate each concept. I would give an overview of person-centred care, highlighting the interactional elements of malignant social psychology and positive person work which are crucial in maintaining or damaging well-being and Self-expression. I would develop vignettes taken from my study and set reflexive exercises which would encourage staff to assess the impact of their interactions on well-being and selfhood of those with dementia in their care. Merging the interactional elements of person-centred care with the structured observational elements of the selfhood approach, would add depth

and meaning to practice; ultimately improving well-being of people with dementia in long-term care and potentially promoting staff satisfaction. A selfhood approach, with its outward looking, searching approach to care, might be easier to teach and be more intuitively appealing for ward staff to use than focusing purely on the person-centred approach, with its focus on looking inwards at one's practice and with its potential for self-blame.

Integrating the selfhood and person-centred approaches in such an innovative staff training and mentoring programme has exciting potential to bring about much needed transformational change in practice.

Regular evaluation would take place using DCM and non-participant observation, in order to evaluate the quality of care and the quality of staff interactions in terms of recognising and supporting Self, and to evaluate patients' responses to such interactions in terms of well/ill-being and expressions of Self.

Key messages

In this section, I lay out what I consider to be key messages arising from this research for practitioners, policy makers and academics, by which such change in practice might be achieved.

Messages for practitioners

It seems that, in the wards of Moorhills Hospital, person-centred care is not happening and that the new culture of care is some way off. Participants frequently experienced ill-being in the wards resulting from limited and

damaging staff interactions, and only occasionally experienced well-being resulting from positive interaction. It seems that an increase in participant well-being was often the unintended consequence of positive interaction rather than the purpose of it. It is imperative that practitioners engage in more positive interactions and in fewer damaging interactions, in order to provide acceptable care. While a person-centred approach to care can achieve this, it is difficult with limited instruction and without ongoing support, and is particularly so in an environment as challenging as Moorhills Hospital.

An approach to caring for people with dementia, which compliments and extends on a person-centred approach, involves looking for and supporting Self-expression of people with dementia, for which I have argued above. This could stimulate a different way of caring, in which practitioners look outwards and respond to verbal and visual expressions of Selfs 1-3. This approach, while requiring instruction, may be easier to achieve than a purely person-centred approach in that its outward looking stance is less likely to result in self-blame, and its emphasis on looking for and supporting unique expressions of Self can bring immediate staff rewards.

Training in reflexivity is essential for achieving person-centred/selfhood care. There is also a need for continuous monitoring of whether person-centred/selfhood care is actually happening. This can be achieved by regular evaluations using a toolkit approach.

Messages for policy makers

In settings where person-centred care is not happening, there is the potential for some serious violations of human dignity to occur. This is contrary to policy statements, which seek to ensure dignity in older age (SEDH, 2006a; SEDH, 2006b).

There must be ongoing consciousness-raising with ward staff of an enduring Self and of the importance of maintaining the dignity of people with dementia. An "in-the-field" person-centred/selfhood training and mentoring programme from a skilled practitioner could achieve this.

There is an urgent need to ensure that student nurses on placement receive "in-the-field" mentoring from a skilled person-centred practitioner. At present, they receive little support. This is a serious state of affairs if they are placed in a setting in which person-centred care is minimal or absent, as there is a risk that they will inadvertently perpetuate the old culture of dementia care.

An organisation in which staff feel valued and supported and where innovative care is encouraged is more likely to produce staff who are content and committed to their work. Thus nurturing the personhoods of staff is vital if they are to nurture the personhoods of their patients (Packer, 2000a).

Messages for academia

There is a need to bring theory to practice in ways that are accessible to care staff. There is an obligation on those with expert knowledge of dementia care to share this with practitioners in their workplaces as opposed to classrooms,

lecture theatres etc. This could be achieved by distributing posters of current thinking on dementia care or by regular teaching or awareness sessions in the wards. By bringing academics and practitioners together, with the common focus of improving the quality of care that people with dementia receive, some of the perceived differences between these two groups could be broken down.

Contribution to the body of knowledge

This study has contributed to the body of knowledge in several ways; methodological, theoretical and practical. I will discuss each in turn.

Methodological contribution

This study took an innovative toolkit approach to data-collection (Innes and Kelly, 2007), using non-participant observation, DCM, video-recording, focused conversations and keeping extensive fieldnotes. By these means, I was able to capture a greater depth of data than had I relied on one method alone. By using this range of methods, I was able to build up a multi-layered understanding of participants' social worlds and of how different interaction types influenced their well-being and Self-expression.

By showing some participants downloaded footage of themselves taking part in a creative session, and by using this to prompt our conversations, I have built on the range of methods used, which seek the views of people with dementia.

By applying Sabat's (2001) Selfs 1-3 framework in the analysis of video-footage and fieldnotes, I was able to identify verbal and visual expressions of Self; even in those with severe cognitive decline. This added further structure to the

analysis, while also widening my interpretation and understanding of participants' Self-expression.

Theoretical contribution

Using symbolic interactionism and social constructionism, I have linked Kitwood's (1997) person-centred approach with Sabat's (2001) work on selfhood. By observing, documenting and comparing interactions encountered by participants in everyday ward life and creative sessions, I have not only exposed how different staff groups engaged in different interaction types, but I have illustrated how such interactions profoundly affected participants' well-being and the robustness of their Self-expression. I have shown that sustained positive interactions from OTs during creative sessions alleviated ill-being and transformed a fragile expression of Self into a robust expression of Self. In so doing, I have added a further dimension to theoretical knowledge on dementia. I have also integrated the person-centred and selfhood approaches to show how Self may be recognised and supported or unrecognised and unsupported, with resultant fluctuations in well/ill-being of participants. These theoretical contributions have implications for practice; for understanding the transactional role of interactions in damaging or nurturing well-being and Self.

I have developed the body of research, which uses Sabat's (2001) Selfs 1-3 and have expanded on his work by identifying the sometimes subtle, fleeting visual expressions of Self that most often go unnoticed in everyday ward life. This theoretical contribution stresses that those with profound communication difficulties will still express Self, however, it is up to practitioners to recognise and respond to such Self-expression. This contribution must further challenge

those who subscribe to ideas on loss of self as dementia progresses. I have also contributed to Sabat's (2001) work by identifying fragile expressions of Self, which are negative expressions of Self in the context of ill-being. This is an important contribution to theory because by attributing meaning to negative Self-expression in the context of ill-being, it further implicates poor social and environmental conditions, as opposed to increasing cognitive decline, as contributors to ill-being.

I have pointed to limitations in DCM for documenting expressions of Self and critiqued the Selfs 1-3 framework for not including a spiritual or "beingness" dimension to Self. As DCM, now in its 8th edition (Brooker and Surr, 2005), has not yet accounted for Self-expression, this limitation will persist. However, Sabat's (2001) work, being less prescriptive, has the potential to be expanded to include these less tangible aspects of Self. There is scope here for a revisioning of theoretical knowledge on selfhood of people with advanced dementia, and this research has taken the first step to this end.

I have demonstrated, in terms of WIB values, the power of creative sessions to increase well-being of those with dementia who take part. This contribution provides much needed empirical evidence to support the therapeutic claims of creativity in dementia care, and particularly in raising well-being of those in long-term care.

In a final contribution to theory, I have positioned myself in social constructionist terms as a rebel; as someone who has highlighted the poor state of affairs in

dementia care and who will strive to bring about a change in thinking and practice through a person-centred/selfhood approach in "in-the-field" training of ward staff.

Practical contribution

In the wards, the "new culture" of dementia care seems some way off, but it is evident in the practice of the OT staff. This raises questions about the types of training/support (or not) that different groups of practitioners receive within a care setting, with huge implications in terms of well/ill-being of patients under the care of these different groups of practitioners. I have suggested an approach which could bring about transformational change in practice; integrating the person-centred and selfhood approaches, as discussed above. This has intuitive appeal; encouraging ward staff to not only look inwards at their own interactional practice, but to look outwards to the Self-expressions of those for whom they care. By recognising and supporting Self of their patients, ward staff should see them as purposeful, sentient beings, thus prompting more positive interactions. This not only has the potential to increase the well-being of their patients, but to ensure that the working lives of ward staff are more satisfying.

Future research

As my study focused specifically on the social worlds of participants with dementia, it has not ascertained why ward and OT staff interacted in such different ways with participants; it has only given tentative reasons based on symbolic interactionist and social constructionist thinking and research. Further research, which might include observations and in-depth interviews, would be

useful in exploring staff perceptions in order to gain a deeper understanding of why they interacted in such different ways.

While I advocate integration of the person-centred and selfhood approaches, its effectiveness in promoting change in practice will only be established through future research. This would be an exciting piece of applied research, which I hope to conduct, possibly using the extended Medical Research Council (MRC) framework for the development and evaluation of complex interventions (Campbell et al., 2007). This framework was designed to enable health service researchers to provide convincing evidence for the success, or otherwise, of a complex intervention. It lays out key tasks for defining and understanding a problem and for optimising the intervention and the evaluation. As such, it would ensure credibility and rigor in this potentially complex piece of evaluation research.

Conclusion

This was a six-month ethnographic study, grounded in symbolic interactionism and social constructionism, which took place in three long-term wards of a hospital. Taking a toolkit approach to data-collection, I explored the types of interactions encountered by 14 participants with dementia during their everyday ward lives and weekly creative sessions facilitated by OT staff. Using Kitwood's (1997) person-centred and Sabat's (2001) selfhood approaches, I documented how interaction types influenced participants' well-being and Self-expression.

My findings are a poor reflection on the quality of long-term care that people with dementia receive in the 21st century. They revealed that everyday staff

interactions with participants, while sometimes positive, were more often limited in their potential for maintaining or increasing participants' well-being. Sometimes staff interactions were abusive, causing participant ill-being. Those least able to initiate or sustain interaction due to cognitive or mobility difficulties, were most at risk of experiencing ill-being. During creative sessions, participants experienced sustained positive interactions from OT staff which increased their well-being, as evidenced by their expressions of pleasure and pride and increasing self-confidence.

I observed many verbal and visual expressions of Self, although some of these were subtle, fleeting and fragile. While OTs generally recognised and supported Selfs 1-3 during creative sessions; transforming fragile expressions of Self into robust expressions of Self and raising participants' well-being, ward staff, while recognising Self 1, were less likely to recognise Selfs 2 and 3 and seldom supported Self; often resulting in participant ill-being.

In response to my findings, I have argued for an intuitively appealing and theory-based approach to caring for people with dementia: integrating the person-centred and selfhood approaches. This has the potential to bring about transformational change in practice, in which care staff, looking outwards towards the person for whom they care, seek and respond to aspects of Self. This would require in-the-field training and mentoring in order to achieve a change in thinking and practice, along with evaluation to assess its effectiveness. I have laid out key messages for practitioners, policy-makers and academics, which could also contribute to changes in practice.

While this study is limited by its relatively small size, it has contributed to methodological, theoretical and practical knowledge on dementia and dementia care. It has used a multi-method ethnographic approach, in order to gain as deep an understanding as possible of participants' social worlds. It has developed Sabat's (2001) Selfs 1-3 framework to include a fragile expression of Self and, by integrating the person-centred and selfhood approaches, it has provided a deeper understanding of the transactional nature of interactions in contributing to well or ill-being. While this is of particular relevance to those in long-term care, it could be applied to the interactional experiences of all those with dementia. Finally, it argues for an innovative, intuitively appealing and potentially transformative development to caring for people with dementia: a person-centred/selfhood approach to care.

This study and the writing of the thesis has been a journey of discovery, academically, professionally and personally. Entering a fearful and painful world beyond my imagining, I encountered a humanity and gentleness amongst my participants that has profoundly moved me. Their humanity shone through the, sometimes, inhumane care they received; showing me a resilience of Self or of spirit that transcended their everyday experiences in the wards. Much work needs to be done to provide care that is fitting to their enduring humanity.

References

Addis, D.R. and Tippett, L. (2004) "Memory of myself: Autobiographical memory and identity in Alzheimer's disease", *Memory*, 12(1):56-74.

Agar, M. (1996) *The Professional Stranger* (2nd ed.) London, Academic Press.

Albrecht, G. (1985) "Videotape Safaris: Entering the Field with a Camera", *Qualitative Sociology*, 8(4):325-344.

Allan, K. and Killick, J. (2000) "Undiminished possibility: the arts in dementia care", *Journal of Dementia Care*, 8(3):16-18.

Andrews, M. (1999) "The seductiveness of agelessness", *Ageing and Society*, 19:301-318.

Archibald, C. (2002) "Sexuality and dementia in residential care – whose responsibility?", *Sexual and Relationship Therapy*, 17(3):301-309.

Armstrong-Esther, C., Browne, K. and McAfee, J. (1994) "Elderly patients: still clean and sitting quietly", *Journal of Advanced Nursing*, 19:264-271.

Baker, A. (2004) "The use of sandtray with older adult clients", in Magniant, R. (ed.) *Art therapy with older adults*, Illinois, Charles C. Thomas.

Ball, M. and Smith, G. (2001) "Technologies of Realism? Ethnographic Uses of Photography and Film", in Atkinson, P., Coffey, A., Delamont, S., Lofland, J. and Lofland, L. (eds.) *Handbook of Ethnography*, London, Sage.

Bannister, P., Burman, E., Parker, I., Taylor, M. and Tindal, C. (2001) *Qualitative Methods in Psychology: A research guide*, Buckingham, The Open University Press.

Barnett, E. (2000) *Including the Person with Dementia in Designing and Delivering Care: "I Need to be Me!"*, London, Jessica Kingsley Publishers.

Baszanger, I. and Dodier, N. (1997) "Ethnography: Relating the Part to the Whole", in Silverman, D. (ed.) *Qualitative Research, Theory, Method and Practice*, London, Sage.

Beard, R. (2004) "In their voices: Identity preservation and experiences of Alzheimer's disease", *Journal of Aging Studies*, 18:415-428.

Bender, M. and Cheston, R. (1997) "Inhabitants of a Lost Kingdom: A Model of the Subjective Experiences of Dementia", *Ageing and Society*, 17:513-532.

Berger, P. (1963) *Invitation to Sociology*, Garden City, New York, Doubleday.

Berger, P. and Luckmann, T. (1966) *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*, Middlesex, Penguin Books Ltd.

Biggs, S. (1997) "Choosing Not To Be Old? Masks, Bodies and Identity Management in Later Life", *Ageing and Society*, 17:553-570.

Blumer, H. (1962) "Society as Symbolic Interaction", in Manis, J. and Meltzer, B. (eds.) *Symbolic Interaction: A Reader in Social Psychology*, Boston, Allyn and Bacon.

Blumer, H. (1969) *Symbolic Interactionism: Perspective and Method*, Englewood Cliffs, NJ, Prentice Hall.

Bond, J. (1992) "The Medicalization of Dementia", *Journal of Aging Studies*, 6(4):397-403.

Bond, J., Briggs, R. and Coleman, P. (1993) "The Study of Ageing", in Bond, J., Coleman, P. and Peace, S. (eds.) *Ageing in Society: an introduction to social gerontology*, (2nd ed.) London, Sage.

Bond, J. and Corner, L. (2004) *Quality of life and older people*, Berkshire, Open University Press.

Bond, J., Corner, L. and Graham, R. (2004) "Social Science Theory on Dementia Research: Normal Ageing, Cultural Representation and Social Exclusion", in Innes, A., Archibald, C. and Murphy, C. (eds.) *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice,* London, Jessica Kingsley Publishers.

Boyle, M. (2000) "Diagnosis, science and power", in Barker, P. and Stevenson, C. (eds.) *The Construction of Power and Authority in Psychiatry*, Oxford, Butterworth Heinemann.

Bradford Dementia Group (1997) *Dementia Care Mapping Manual,* (7th ed.), Bradford, University of Bradford.

Bredin, K. and Kitwood, T. (1995) "Decline in quality of life for patients with severe dementia following a ward merger", *International Journal of Geriatric Psychiatry*, 10:967-973.

Brooker, D. (2002) "Dementia Care Mapping: a look at its past, present and future", *Journal of Dementia Care*, May/June:33-36.

Brooker, D. (2003) "Future Challenges for Dementia Care Mapping", in Innes, A. (ed.) *Dementia Care Mapping: Applications Across Cultures*, Baltimore, Health Professions Press.

Brooker, D. (2004) "What is person-centred care in dementia?", *Reviews in Clinical Gerontology*, 13:215-222.

Brooker, D. and Duce, L. (2000) "Wellbeing and activity in dementia: a comparison of group reminiscence therapy, structured goal-directed activity and unstructured time", *Aging & Mental Health*, 4(4):354-358.

Brooker, D. and Surr, C. (2005) *Dementia Care Mapping: Principles and Practice*, (8th ed.) Bradford, University of Bradford.

Brooker, D., Foster, N., Banner, A., Payne, M. and Jackson, L. (1998) "The efficacy of Dementia Care Mapping as an audit tool: report of a 3-year British NHS evaluation", *Aging & Mental Health*, 2(1):60-70.

Bryden, C. (2005) *Dancing with Dementia: My Story of Living Positively with Dementia*, London, Jessica Kingsley Publishers.

Bulmer, M. (2001) "The Ethics of Social Research", in Gilbert, N. (ed.) *Researching Social Life* (2nd ed.) London, Sage.

Burkitt, I. (1998) "Bodies of Knowledge: Beyond Cartesian Views of Persons, Selves and Minds", *Journal for the Theory of Social Behaviour*, 28(3):63-82.

Bury, M. (1986) "Social constructionism and the development of medical sociology", *Sociology of Health & Illness*, 8(2):137-169.

Bury, M. and Holme, A. (1991) *Life after ninety*, London, Routledge.

Bytheway, B. (1997) *Ageism*, Buckingham, Open University Press.

Campbell, N., Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F., Guthrie, B., Lester, H., Wilson, P. and Kinmonth, A. (2007) "Designing and evaluating complex interventions to improve health care", *British Medical Journal*, 334:455-459.

Cantley, C. and Bowes, A. (2004) "Dementia and Social Inclusion: The Way Forward", in Innes, A., Archibald, C. and Murphy, C. (eds.) *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice*, London, Jessica Kingsley Publishers.

Capstick, A. (2003) "The Theoretical Origins of Dementia Care Mapping", in Innes, A. (ed.) *Dementia Care Mapping: Applications Across Cultures*, Baltimore, Health Professions Press.

Charon, J. (2007) *Symbolic Interactionism: An Introduction, An interpretation, An Integration*, New Jersey, Pearson Prentice Hall.

Chatterji, J. (1998) "An ethnography of dementia: A case study of an Alzheimer's disease patient in the Netherlands", *Culture, Medicine and Psychiatry*, 22:355-382.

Chaudhury, H. (2003) "Remembering Home Through Art", *Alzheimer's Care Quarterly*, 4(2):119-124.

Clare, L. (2003) "Managing threats to self: awareness in the early stage of Alzheimer's disease", *Social Science & Medicine*, 57:1017-1029.

Clarke, A., Hanson, E. and Ross, H. (2003) "Seeing the person behind the patient: enhancing the care of older people using a biographical approach", *Journal of Clinical Nursing*, 12:697-706.

Clarke, R. (2004) "Precious experiences beyond mere words", *Journal of Dementia Care*, May/June:22-23.

Cohen, D. and Eisdorfer, C. (1986) *The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders*, New York and London, W.W. Norton & Company.

Cohen-Mansfield, J., Golander, H. and Arnheim, G. (2000) "Self-identity in older persons suffering from dementia: preliminary results", *Social Science & Medicine*, 51:381-394.

Coleman, P. (1993) "Psychological Ageing", in Bond, J., Coleman, P. and Peace, S. (eds.) *Ageing in Society: an introduction to social gerontology*, (2nd ed.) London, Sage.

Coleman, P. and Mills, M. (2001) "Philosophical and Spiritual Perspectives", in Cantley, C. (ed.) *A Handbook of Dementia Care*, Buckingham, Open University Press.

Coleman, P., Bond, J. and Peace, S. (1993) "Ageing in the Twentieth Century", in Bond, J., Coleman, P. and Peace, S. (eds.) *Ageing in Society: an introduction to social gerontology*, (2nd ed.) London, Sage.

Collier, J. Jr. (1967) *Visual Anthropology: Photography as a Research Method*, New York, Holt, Rinehart and Winston.

Cook, A. (2002) "Using video observation to include the experiences of people with dementia in research", In Wilkinson, H. (ed.) *The Perspectives of People with Dementia: Research Methods and Motivations,* London, Jessica Kingsley Publishers.

Cook, A. (2003) *Understanding the communication of older people with dementia living in residential care*, Unpublished Ph.D. Thesis, Stirling, University of Stirling.

Cotrell, V. and Hooker, K. (2005) "Possible Selves of Individuals With Alzheimer's Disease", *Psychology and Aging*, 20(2):285-294.

Cowdell, F. (2006) "Preserving personhood in dementia research: a literature review", *International Journal of Older People Nursing*, 1:85-94.

Cox, S. and Watchman, K. (2004) "Death and Dying", in Innes, A., Archibald, C. and Murphy, C. (eds.) *Dementia and Social Inclusion: Marginalised Groups and*

Marginalised Areas of Dementia Research, Care and Practice, London, Jessica Kingsley Publishers.

Craig, C. (2001) *Celebrating the Person: A Practical Approach to Arts Activities*, Stirling, Dementia Services Development Centre.

Cumming, E. and Henry, W. (1961) *Growing Old: The Process of Disengagement*, New York, Basic Books.

Davis, D. (2004) "Dementia: sociological and philosophical constructions", *Social Science & Medicine*, 58:369-378.

Denny, J. (1975) "Techniques for Individual and Group Art Therapy", in Ulman, E. and Dachinger, P. (eds.) *Art Therapy in Theory and Practice*, New York, Schocken Books.

Descartes, R. (1640) "Meditations on the First Philosophy in which the Existence of God and the Distinction Between Mind and Body are Demonstrated", in Wilkinson, R. (2002) *Minds and Bodies*, Milton Keynes, The Open University.

Dewing, J. (2002) "From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have a dementia", *Dementia,* 1:157-171.

Dewing, J. (2004) "Concerns relating to the application of frameworks to promote person-centeredness in nursing with older people", *International Journal of Older People Nursing*, 13, 3a:39-44.

Downs, M. (1997) "The Emergence of the Person in Dementia Research", *Ageing and Society*, 17:597-607.

Downs, M., Clare, L. and Mackenzie, J. (2006) "Understandings of dementia: explanatory models and their implications for the person with dementia and therapeutic effort", in Hughes, J., Louw, S. and Sabat, S. (eds.) *Dementia: mind, meaning and the person*, Oxford, Oxford University Press.

Edelman, P., Kuhn, D. and Fulton, B.R. (2004) "Influence of cognitive impairment, functional impairment and care setting on Dementia Care Mapping results", *Aging & Mental Health*, 8(6):514-523.

Edwards, P. (2005) "Putting Dementia Care Mapping on the map", *Journal of Dementia Care*, Jan/Feb:16-17.

Elias, N. (1985) *The Loneliness of the Dying*, (trans. Jephcott, E.), Oxford, Blackwell.

Estes, C. and Binney, E. (1989) "The Biomedicalization of Aging: Dangers and Dilemmas", *The Gerontologist*, 29(5):587-596.

Faulkner, M. (2001) "The onset and alleviation of learned helplessness in older hospitalized people", *Ageing & Mental Health*, 5(4):379-386.

Fazio, S. (2001) "Person-Centred Language is an Essential Part of Person-Centred Care", *Alzheimer's Care Quarterly*, 2(2):87-90.

Fielding, N. and Thomas, H. (2001) "Qualitative interviewing", in Gilbert, N. (ed.) *Researching Social Life* (2nd ed.), London, Sage.

Folstein, M., Folstein, S. and McHugh, P. (1975) "Mini-mental state exam: A practical method for grading the cognitive states of patients for the clinician", *Journal of Psychiatric Research*, 12:189-198.

Fontana, A. and Smith, R. (1989) "Alzheimer's disease victims: the 'unbecoming' of self and the normalization of competence", *Sociological Perspectives*, 32(1):35-46.

Fossey, J., Lee, L. and Ballard, C. (2002) "Dementia Care Mapping as a research tool for measuring quality of life in care settings: psychometric properties", *International Journal of Geriatric Psychiatry*, 17:1064-1070.

Friedell, M. (2002) "Awareness: a personal memoir on the declining quality of life in Alzheimer's", *Dementia*, 1(3):359-366.

Gallagher-Thompson, D., Dal Canto, P.G., Darnley, S., Basilio, L.A., Whelan, L. and Jacob, T. (1997) "A feasibility study of videotaping to assess the relationship between distress in Alzheimer's disease caregivers and their interaction style", *Aging & Mental Health*, 1(4):346-355.

Geertz, C. (1973) *The Interpretation of Cultures*, New York, Fontana Press.

Gergen, K. (1985) "The Social Constructionist Movement in Modern Psychology", *American Psychologist*, 40(3):266-275.

Gingold, R. (1992) *Successful Ageing*, Oxford, Oxford University Press.

Glaser, B.G. and Strauss, A.L. (1967) *The Discovery of Grounded Theory*, Chicago, Aldine.

Goffman, E. (1961) *Asylums*, London, Penguin Books.

Goffman, E. (1968) *Stigma*, Englewood Cliffs, Prentice Hall.

Goldman, L. (2004) "Art therapy and Alzheimer's disease: my mother's art", in Magniant, R. (ed.) *Art Therapy with Older Adults: A Sourcebook*, Illinois, Charles C. Thomas Publisher.

Goldsmith, M. (1996) *Hearing the Voice of People with Dementia: Opportunities and Obstacles*, London, Jessica Kingsley Publishers.

Goyder, J. (2001) *We'll be Married in Fremantle: Alzheimer's Disease and the Everyday Act of Storying*, Fremantle, Fremantle Arts Centre Press.

Greene Stewart, E. (2002) "de Kooning's dementia", *American Journal of Alzheimer's Disease and Other Dementias*, 17(5):313-317.

Gubrium, J. and Holstein, J. (1999) "The nursing home as a discursive anchor for the aged body", *Ageing and Society*, 19:519-538.

Hacking, I. (1999) *The Social Construction of What?*, Cambridge, Mass., Harvard University Press.

Hadden, S. and Lester, M. (1978) "Talking Identity: The Production of 'Self' In Interaction", *Human Studies*, 1:331-356.

Hammersley, M. and Atkinson, P. (1983) *Ethnography: principles in practice*, New York, Tavistock Publications.

Harding, N. and Palfrey, C. (1997) *The Social Construction of Dementia: Confused Professionals?*, London, Jessica Kingsley Publishers.

Harison, B. (1996) "Every Picture 'Tells a Story': Uses of the Visual in Sociological Research", in Stina Lyon, E. and Busfield, J. (eds.) *Methodological Imaginations,* London, Macmillan Press Ltd.

Harlan, J. (1993) "The Therapeutic Value of Art for Persons with Alzheimer's Disease and Related Disorders", *Loss, Grief and Care*, 6(4):99-106.

Harré, R. (1983) *Personal Being: A Theory for Individual Psychology*, Oxford, Basil Blackwell.

Harris, P. and Sterin, G. (1999) "Insider's Perspective: Defining and Preserving the Self in Dementia", *Journal of Mental Health and Aging*, 5(3):241-256.

Hauser, A. (1974) *The Sociology of Art*, (trans. Northcott, K. 1982), London, Routledge and Kegan Paul Ltd.

Haveven, T. (1995) "Changing images of ageing and the social construction of the life course", in Fetherstone, M. and Wernick, A. (eds.), *Images of Aging: Cultural Representations of Later Life*, London, Routledge.

Heath, C. (2004) "Analysing face-to-face interaction: video and the visual and the material", in Silverman, D. (ed.) *Qualitative Research: Theory, Method and Practice*, (2nd ed.) London, Sage.

Hellen, C. (2000) "Being, Doing, Belonging: Upholding the Sense of Self with Meaningful Activities", *Alzheimer's Care Quarterly*, 1(1):35-49.

Herskovits, E. (1995) "Struggling over Subjectivity: Debates about the 'Self' and Alzheimer's Disease", *Medical Anthropology Quarterly*, 9(2):146-164.

Hinton, W.L. and Levkoff, S. (1999) "Constructing Alzheimer's: narratives of lost identities, confusion and loneliness in old age", *Culture, Medicine and Psychiatry*, 22:453-475.

HMSO (2000) Adults with Incapacity (Scotland) Act. http://www.scotland.gov.uk/Topics/Justice/Civil/16360/4927

Hochschild, A. (1983) *The Managed Heart*, Berkeley, University of California Press.

Hodder, R. (2004) "A Painting of Loss and Grief", *Illness, Crisis & Loss*, 12(4):319-336.

Holstein, J. and Gubrium, J. (1997) "Active interviewing", in Silverman, D. (ed.) *Qualitative Research: Theory, Method and Practice*, London, Sage.

Holstein, J. and Gubrium, J. (2000) *The Self We Live By*, Oxford, Oxford University Press.

Hubbard, G., Cook, A., Tester, S. and Downs, M. (2002a) "Beyond words: Older people with dementia using and interpreting nonverbal behaviour", *Journal of Aging Studies*, 16:155-167.

Hubbard, G., Downs, M. and Tester, S. (2002b) "Including the perspectives of older people in institutional care during the consent process", in Wilkinson, H. (ed.) *The Perspectives of People with Dementia: Research Methods and Motivations*, London, Jessica Kingsley Publishers.

Hughes, B. (2002) "Bauman's Strangers: impairment and the invalidation of disabled people in modern and post-modern cultures", *Disability and Society*, 17(5):571-584.

Hughes, J. (2001) "Views of the person with dementia", *Journal of Medical Ethics*, 27:86-91.

Hulko, W. (2004) "Social Science Perspectives on Dementia Research: Intersectionality", in Innes, A., Archibald, C. and Murphy, C. (eds.) *Dementia and Social Inclusion*, London, Jessica Kingsley Publishers.

Hurd, L. (1999) "'We're not old!': Older Women's Negotiation of Aging and Oldness", *Journal of Aging Studies*, 13(4):419-439.

Iacoco, T. and Murray, V. (2003) "Issues of Informed Consent in Conducting Medical Research Involving People with Intellectual Disability", *Journal of Applied Research in Intellectual Disabilities*, 16:41-51.

Innes, A. (2002) "The social and political context of formal dementia care provision", *Ageing and Society*, 22:483-499.

Innes, A. and Capstick, A. (2001) "Communication and Personhood", in Cantley, C. (ed.) *A handbook of dementia care*, Buckingham, Open University Press.

Innes, A. and Kelly, F. (2007) "Evaluating Long Stay Settings: Reflections on the Process with Particular Reference to Dementia Care Mapping", in Innes, A. and McCabe, L. (eds.) *Evaluation in Dementia Care*, London, Jessica Kingsley Publishers.

Innes, A. and Surr, C. (2001) "Measuring the well-being of people with dementia living in formal care settings: the use of Dementia Care Mapping", *Aging & Mental Health*, 5(3):258-268.

Innes, A., Capstick, A. and Surr, C. (2000) "Mapping out the framework", *Journal of Dementia Care*, March/April:20-21.

Jensen, S. and Wheaton, M. (1997) "Multiple Pathways to Self: A Multisensory Art Experience", *Journal of the American Art Therapy Association*, 14(3):178-186.

Katz, S. (2000) "Busy Bodies: Activity, Aging and the Management of Everyday Life", *Journal of Aging Studies*, 14(2):135-152.

Kaufman, S., Shim, J. and Russ, A. (2004) "Revisiting the Biomedicalization of Aging: Clinical Trends and Ethical Challenges", *The Gerontologist*, 44(6):731-738.

Kelly, M. and Field, D. (1996) "Medical sociology, chronic illness and the body", *Sociology of Health & Illness*, 18(2):241-257.

Killick, J. and Allan, K. (2001) *Communication and the care of people with dementia*, Buckingham, Open University Press.

Kitwood, T. (1990) "The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease", *Ageing and Society*, 10:177-196.

Kitwood, T. (1997) *Dementia Reconsidered: The Person Comes First*, Buckingham, Open University Press.

Kitwood, T. and Bredin, K. (1992) "Towards a theory of dementia care: personhood and well-being", *Ageing and Society*, 12:269-287.

Klein, S., Cosmides, L. and Costabile, K. (2003) "Preserved knowledge of self in a case of Alzheimer's dementia", *Social Cognition*, 21(2):157-165.

Kneller, G. (1965) *The Art and Science of Creativity*, New York, Holt, Rinehart and Winston Inc.

Kondo, D. (1990) *Crafting Selves: Power, Gender and Discourses of Identity in a Japanese Workplace*, Chicago, Chicago University Press.

Kontos, P. (1998) "Resisting Institutionalization: Constructing Old Age and Negotiating Home", *Journal of Aging Studies*, 12(2):176-184.

Kontos, P. (2003) "The painterly hand: embodied consciousness and Alzheimer's disease", *Journal of Aging Studies*, 17:151-170.

Kontos, P. (2004) "Ethnographic reflections on selfhood, embodiment and Alzheimer's disease", *Aging & Society*, 24:829-849.

Kontos, P. (2005) "Embodied selfhood in Alzheimer's disease", *Dementia*, 4(4):553-570.

Kuhn, D., Ortigara, A. and Kasayka, R. (2000) "Dementia Care Mapping: An innovative tool to measure Person-Centred Care", *Alzheimer's Care Quarterly*, 1(3):7-15.

Laing, R.D and Esteron, A. (1964) *Sanity, Madness and the Family*, Middlesex, Penguin Books.

Laing, R.D. (1961) *The Self and Others: further studies in sanity and madness*, London, Tavistock.

Lee-Treweek, G. (2000) "The insight of emotional danger: research experiences in a home for older people", in Lee-Treweek, G. and Linkogle, S. (eds.) *Danger in the field: risk and ethics in social research*, London and New York, Routledge.

Leslie, H. (2001) "Dementia and Art", *Nursing Older People*, 13(7):10-13.

Li, R. and Orleans, M. (2002) "Personhood in a World of Forgetfulness: An Ethnography of the Self-Process Among Alzheimer's Patients", *Journal of Aging and Identity*, 7(4):227-244.

Lloyd, C. and Papas, V. (1999) "Art as Therapy within Occupational Therapy in Mental Health Settings: A Review of the Literature", *British Journal of Occupational Therapy*, 62(1):31-34.

Lomax, H. and Casey, N. (1998) "Recording Social Life: Reflexivity and Video Methodology", *Sociological Research Online*, retrieved from http://www.socresonline.org.uk/socresonline/3/2/1.html

Lyman, K. (1989) "Bringing the Social Back in: A Critique of the Biomedicalization of Dementia", *The Gerontological Society of America*, 29(5): 597-605.

Mackenzie, L., James, I. and Lee, L. (2002) "How DCM feedback procedures can be improved", *Journal of Dementia Care*, Sept/Oct:23-25.

Maduro, R. (1974) "Artistic Creativity and Aging in India", *International Journal of Aging and Human Development*, 5: 303-329.

Mancuso, J. (1996) "Constructionism, Personal Construct Psychology and Narrative Psychology", *Theory and Psychology*, 6(1):47-70.

Marshall, M. (2001) "Care settings and the care environment", in Cantley, C. (ed.) *A handbook of dementia care*, Buckingham, Open University Press.

Marshall, M. and Hutchinson, S. (2001) "A critique of research on the use of activities with persons with Alzheimer's disease: a systematic literature review", *Journal of Advanced Nursing*, 35(4):488-496.

Mason, J. (2002) *Qualitative Researching* (2nd ed.), London, Sage.

Mayhew, P., Acton, G., Yauk, S. and Hopkins, B. (2001) "Communication from Individuals with Advanced DAT: Can it Provide Clues to Their Sense of Self-Awareness and Well-being?", *Geriatric Nursing*, 22(2):106-110.

McColgan, G. (2004) "Images, Constructs, Theory and Method: Including the Narrative of Dementia", in Innes, A., Archibald, C. and Murphy, C. (eds.) *Dementia and Social Inclusion*, London, Jessica Kingsley Publishers.

McCormack, B. (2004) "Person-centredness in gerontological nursing: an overview of the literature", *International Journal of Older People Nursing in association with the Journal of Clinical Nursing*, 13 (3a):31-38.

McHugh, K. (2003) "Three faces of ageism: society, image and place", *Ageing and Society*, 23:165-185.

McKillop, J. and Wilkinson, H. (2004) "Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed", *Dementia*, 3(2):117-125.

McNiff, S. (1994) *Art as Medicine: Creating a Therapy of the Imagination*, London, Piatkus Books.

Mead, G.H. (1934) *Mind, Self and Society*, Chicago, Chicago University Press.

Meltzer, B., Petras, J. and Reynolds, L. (1980) *Symbolic Interactionism: genesis, varieties and criticism*, London, Routledge and Kegan Paul.

Messman, K. (2004) "Finding her wisdom: journey of an older woman", in Magniant, R. (ed.) *Art therapy with older adults*, Illinois, Charles C. Thomas.

Miles, M. and Huberman, M. (1994) *Qualitative Data Analysis: An Expanded Sourcebook*, (2nd ed.), London, Sage.

Mottram, P. (2003) "Art therapy with clients who have dementia", *Dementia*, 2(2):272-277.

Naumberg, M. (1975) "Spontaneous Art in Education and Psychotherapy", in Ulman, E. and Dachinger, P. (eds.) *Art Therapy In Theory and Practice*, New York, Schocken Books.

Neel, A. (2002) "How DCM may affect caregiver mappers", *Journal of Dementia Care*, July/Aug:26-28.

Nolan, M., Grant, G. and Nolan, J. (1995) "Busy doing nothing: activity and interaction levels amongst differing populations of elderly patients", *Journal of Advanced Nursing*, 22:528-538.

Norbergh, K., Asplund, K., Rassmussen, B., Nordahl, G. and Sandman, P. (2001) "How patients with dementia spend their time in a psycho-geriatric unit", *Scandinavian Journal of Caring Sciences*, 15:215-221.

Orona, C. (1997) "Temporality and Identity Loss Due to Alzheimer's Disease", in Strauss, A. and Corbin, J. (eds.) *Grounded Theory in Practice*, London, Sage.

Osler, I. (1988) "Creativity's influence on a case of dementia", *Inscape*, Summer:20-22.

Øyvind, K. (2007) "Evaluating Long Stay Interventions: Concealment of Medication", in Innes, A. and McCabe, L. (eds.) *Evaluation in Dementia Care*, London, Jessica Kingsley Publishers.

Packer, T. (2000a) "A person-centred approach to the people who care", *Journal of Dementia Care*, Nov/Dec:28-30.

Packer, T. (2000b) "Does person-centred care exist?", *Journal of Dementia Care*, May/June:19-21.

Pearce, A., Clare, L. and Pistrang, N. (2002) "Managing sense of self: Coping in the early stages of Alzheimer's disease", *Dementia*, 1(2):173-192.

Phillipson, C. (1982) *Capitalism and the Construction of Old Age*, London, Macmillan Press Ltd.

Phinney, A. (2002) "Fluctuating awareness and the breakdown of the illness narrative in dementia", *Dementia*, 1(3):329-344.

Phinney, A. and Chesla, C. (2003) "The lived body in dementia", *Journal of Aging Studies*, 17:283-299.

Pink, S. (2001) *Doing Visual Ethnography*, London, Sage.

Proctor, G. (2001) "Listening to Older Women with Dementia: relationships, voices and power", *Disability & Society*, 16(3):361-376.

Rentsch, T. (1997) "Aging as Becoming Oneself: A Philosophical Ethics of Late Life", *Journal of Aging Studies*, 11(4):263-271.

Robinson, E. (2002) "Should people with Alzheimer's disease take part in research?", in Wilkinson, H. (ed.) *The Perspectives of People with Dementia*, London, Jessica Kingsley Publishers.

Rogers, C. (1954) "Towards a Theory of Creativity", in Vernon, P.E. (ed.) *Creativity: Selected Readings*, Middlesex, Penguin Books Ltd.

Ronch, J. (1996) "Mourning and grief in late life Alzheimer's dementia: Revisiting the vanishing self", *American Journal of Alzheimer's Disease*, July/August, 25-28.

Roper, J. and Shapira, N. (2000) *Ethnography in Nursing Research*, London, Sage.

Rosenhan, D.L. (1973) "On being sane in insane places", *Science*, 179:250-258.

Rosenstein, B. (2002) "Video Use in Social Science Research and Program Evaluation", *International Journal of Qualitative Methods*, 1(3) retrieved from http://www.ualberta.ca/~iiqm/backissues/1-3Final/html/rosenstein.html

Sabat, S. (2001) *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*, Oxford, Blackwell Publishers Ltd.

Sabat, S. (2002) "Surviving manifestations of Selfhood in Alzheimer's disease", *Dementia*, 1(1):25-36.

Sabat, S. (2005) "Capacity for decision-making in Alzheimer's disease: selfhood, positioning and semiotic people", *Australian and New Zealand Journal of Psychiatry*, 39:1030-1035.

Sabat, S. (2006) "Mind, meaning and personhood in dementia: the effects of positioning", in Hughes, J., Louw, S. and Sabat, S. (eds.) *Dementia: mind, meaning and the person*, Oxford, Oxford University Press.

Sabat, S. and Collins, M. (1999) "Intact social, cognitive ability and selfhood: A case study of Alzheimer's disease", *American Journal of Alzheimer's Disease*, 14(1):11-19.

Sabat, S. and Harré, R. (1992) "The Construction and Deconstruction of Self in Alzheimer's Disease", *Ageing and Society*, 12:443-461.

Sabat, S., Napolitano, L. and Fath, H. (2004) "Barriers to the construction of a valued social identity: A case study of Alzheimer's disease", *American Journal of Alzheimer's Disease and Other Dementias*, 19(3):177-185.

Scottish Executive Health Department (2006a) *Rights, Relationships and Recovery – the Review of Mental Health Nursing in Scotland*, Edinburgh, Scottish Executive.

Scottish Executive Health Department (2006b) *Delivering care, enabling health*, Edinburgh, Scottish Executive.

Seligman, M. (1975) *Helplessness*, San Francisco, Freeman.

Sheard, D. (2004) "Person-centred care: the emperor's new clothes?", *Journal of Dementia Care*, 12(2):22-24.

Sherman, E. and Webb, T. (1994) "The Self as Process in Late Life Reminiscence: Spiritual Attributes", *Ageing and Society*, 14:255-267.

Shotter, J. (1985) "Social accountability and self specification", in Gergen, K. and Davis, K. (eds.) *The Social Construction of the Person*, New York, Springer Verlag.

Shotter, J. (1989) "Social Accountability and the Social Construction of 'you'", in Shotter, J. and Gergen, K. (eds.) *Texts of Identity*, London, Sage.

Silverman, D. (2001) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*, (2nd ed.), London, Sage.

Silverman, D. (2005) *Doing Qualitative Research*, (2nd ed.), London, Sage.

Silverstone, L. (1997) *Art Therapy – The Person-Centred Way*, (2nd ed.), London, Jessica Kingsley Publishers.

Skovdahl, K., Larsson Kihlgren, A. and Kihlgren, M. (2003) "Dementia and aggressiveness: video-recorded morning care from different care units", *Journal of Clinical Nursing*, 12:888-898.

Small, J., Geldart, K., Gutman, G. and Clarke Scott, M. (1998) "The discourse of self in dementia", *Ageing & Society*, 18:291-316.

Snyder, L. (2001) "The Lived Experience of Alzheimer's: Understanding the Feelings and Subjective Accounts of Persons with the Disease", *Alzheimer's Care Quarterly*, 2(2):8-22.

Snyder, L. (2006) "Personhood and interpersonal communication in dementia", in Hughes, J., Louw, S. and Sabat, S. (eds.) *Dementia: mind, meaning and the person*, Oxford, Oxford University Press.

Spaniol, S. (2001) "Art and mental illness: where is the link?", *The Arts in Psychotherapy*, 28:221-231.

Sterin, G. (2002) "Essay on a word: A lived experience of Alzheimer's disease", *Dementia*, 1(1):7-10.

Sterritt, P. and Pokorny, M. (1994) "Art Activities for Patients with Alzheimer's and Related Disorders", *Geriatric Nursing*, 15(3):155-159.

Strauss, A. (1959) *Mirrors and masks: the search for identity*, (2ⁿᵈ ed.) New Brunswick and London, Transaction Publishers.

Surr, C. (2004) *Self in Dementia*, Unpublished Ph.D. Thesis, Bradford, University of Bradford.

Surr, C. and Bonde Neilson, E. (2003) "Inter-rater reliability in Dementia Care Mapping", *Journal of Dementia Care*, Nov/Dec:33-35.

Sweeting, H. and Gilhooly, M. (1997) "Dementia and the phenomenon of social death", *Sociology of Health & Illness*, 19(1):93-117.

Tappen, R., Williams, C., Fishman, S. and Touhy, T. (1999) "Persistence of Self in Advanced Alzheimer's Disease", *Journal of Nursing Scholarship*, 31(2):121-125.

Thornton, A., Hatton, C. and Tatham, A. (2004) "Dementia Care Mapping reconsidered: exploring the reliability and validity of the observational tool", *International Journal of Geriatric Psychiatry*, 19:718-726.

Tornstam, L. (1997) "Gerotranscendence: The Contemplative Dimension of Aging", *Journal of Aging Studies*, 11(2):143-154.

Traphagen, J. (2002) "Senility as disintegrated person in Japan", *Journal of Cross-Cultural Gerontology*, 17:253-267.

Tunis. S., Edell, W., Adams, B. and Kennedy, J. (2002) "Characterising Behavioural and Psychological Symptoms of Dementia (BPSD) Among Geropsychiatric Inpatients", *Journal of the American Medical Directors Association*, 3:146-151.

Twigg, J., and Atkin, K. (1994) *Carers Perceived: Policy and Practice in Informal Care*, Milton Keynes, Open University Press.

Ulman, E. (1975a) "Art Therapy: Problems of Definition", in Ulman, E. and Dachinger, P. (eds.) *Art Therapy In Theory and Practice*, New York, Schocken Books.

Ulman, E. (1975b) "Therapy is Not Enough: The Contribution of Art to General Hospital Psychiatry", in Ulman, E. and Dachinger, P. (eds.) *Art Therapy In Theory and Practice*, New York, Schocken Books.

Usita, P., Hyman, I. Jr. and Herman, K. (1998) "Narrative Intentions: Listening to Life Stories in Alzheimer's Disease", *Journal of Aging Studies*, 12(2):185-197.

Ussher, J. (2000) "Women's Madness: A Material-Discursive-Intrapsychic Approach", in Fee, D. (ed.) *Pathology and the Postmodern: Mental Illness as Discourse and Experience*, London, Sage.

Vass, A., Minardi, H., Ward, R., Garfield, C. and Cybyk, B. (2003) "Research into communication patterns and consequences for effective care of people with Alzheimer's and their carers", *Dementia*, 2(1): 21-48.

Vittoria, A. (1998) "Preserving Selves: Identity Work and Dementia", *Research on Aging*, 20(1):91-136.

Waid, L. and Frazier, L. (2003) "Cultural differences in possible selves during later life", *Journal of Aging Studies*, 17:251-168.

Wald, J. (1983) "Alzheimer's Disease and the Role of Art Therapy in its treatment", *American Journal of Art Therapy*, 22:57-64.

Ward. R., Vass, A., Aggarwal, N., Garfield, C. and Cybyk, B. (2005) "A kiss is still a kiss? The construction of sexuality in dementia care", *Dementia*, 4(1):49-72.

Watson, R. (1997) "Ethnomethodology and textual analysis", in Silverman, D. (ed.) *Qualitative research: Theory, Method and Practice*. London, Sage.

Wilkinson, H. (2002) "Including people with dementia in research: Methods and motivations", in Wilkinson, H. (ed.) *The Perspectives of People with Dementia: Research Methods and Motivations*, London, Jessica Kingsley Publishers.

Wilks, R. and Byers, A. (1994) "Art therapy with elderly people in statutory care", in Waller, D. and Gilroy, A. (eds.) *Art Therapy: A Handbook*, Buckingham, Open University Press.

Williams, J. and Rees, J. (1997) "The use of 'Dementia Care Mapping' as a method of evaluating care received by patients with dementia – an initiative to improve quality of life", *Journal of Advanced Nursing*, 25:316-323.

Wolcott, H. (1995) *The Art of Fieldwork*, London, Sage.

Wood, D., Bruner, J. and Ross, G. (1976) "The role of tutoring in problem-solving", *Journal of Child Psychology and Psychiatry*, 17:89-100.

Wood, M. (1998a) "Art therapy in palliative care", in Pratt, M. and Wood, M. (eds.) *Art Therapy in Palliative Care*, London, Routledge.

Wood, M. (1998b) "What is art therapy?", in Pratt, M. and Wood, M. (eds.) *Art Therapy in Palliative Care*, London, Routledge.

Wood, M. (2002) "Researching art therapy with people suffering from AIDS related dementia", *The Arts in Psychotherapy*, 29:207-219.

Woods, B. and Lintern, T. (2003) "The reliability and Validity of Dementia Care Mapping", in Innes, A. (ed.) *Dementia Care Mapping: Applications Across Cultures*, Baltimore, Health Professions Press.

Woods, R.T. (2001) "Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects", *Aging and Mental Health*, 5(S1):S7-S16.

Wright, P. and Treacher, A. (1982) "Introduction", in Wright, P. and Treacher, A. (eds.) *The Problem of Medical Knowledge: Examining the Social Construction of Medicine*, Edinburgh, Edinburgh University Press.

Zola, I. (1972) "Medicine as an Institution of Social Control", *Sociological Review*, 20(4):487-504.

Appendices

Brief introduction to participants with dementia.

Ward 1

Nora Bridges is 83 and she has a diagnosis of Alzheimer's disease. She also has a history of depression and ischaemic heart disease. She was admitted to the ward in October 2003 because of increasing aggression and agitation at home.

Edward Rankin is 73 with a diagnosis of Alzheimer's disease. He was admitted to the hospital in October 2004 with increasing cognitive decline and inability to manage at home.

Florence McPherson is aged 83 with a diagnosis of epilepsy and moderate dementia. She was admitted to the hospital in October 2004.

Ward 2

Hannah Curtis is 87. She was born in the North of Scotland and was adopted as a young girl. She has a history of anxiety and anorexia and was admitted to the ward in July 2000 with a diagnosis of severe dementia.

Isabel McLeod is 83. She has been diagnosed with vascular dementia and was transferred from a nursing home to the ward in January 2005 due to increased aggression and increasing falls.

Brenda Gordon is 69. She was admitted to the ward in July 2003. She had a long history of memory decline and increasing agitation and was diagnosed with vascular and neurodegenerative dementia in 2002.

Kate Hamilton is 85. She was admitted in December 2001 because of increasing concerns about her ability to manage at home. She has been diagnosed with vascular dementia.

Mary Mitchell is 80. She has a history of depression, anxiety, alcohol misuse and Alzheimer's. She was admitted to the ward in November 2004.

Ward 3

Paul Johnston is 88. He has been profoundly deaf since he sustained a wartime injury. He was diagnosed with fronto-temporal dementia by scan in 2001 following a deterioration in his short-term memory and increasing aggression. He was admitted to hospital in 2002 for assessment of aggression and sexual disinhibition and admitted to ward 3 for long-term care in 2003.

William Fairbairn is 75. He was diagnosed with vascular dementia in 1995 (at the age of 64) following investigation for increasing difficulty with his short-term memory. He was admitted to a nursing home in 2001 but was transferred to ward 3 in 2004 following sexually inappropriate behaviour towards patients and staff.

Bill Armstrong is 86. He has a complex psychiatric history, which includes epilepsy, depression, self-harm, and several attempts at suicide. He was transferred to ward 3 from sheltered housing in 2003 due to increasingly erratic and sexually inappropriate behaviour. He was diagnosed with dementia in 2004 by CT scan.

John Crombie is 79. He has a history of myocardial infarction and CVA. He was diagnosed with vascular dementia by CT scan in 2004 and was admitted to the ward later in 2004 due to increasing aggression and frequent falls.

Charlie Maxwell is 80. He was diagnosed with vascular dementia in 2002 and was admitted to the ward from a nursing home in 2004 with increasing aggression, paranoia, confusion and sexual disinhibition.

Kevin Peterson is 86. He was admitted to the hospital in 2002 for assessment of increasing aggression, disorientation and difficulties with his balance. He was subsequently admitted to ward 3 for long-term care in 2003. He has a history of transient ischaemic attacks and he continues to experience them regularly. He was diagnosed with vascular dementia by CT scan in 2002.

Behaviour Category Codes

A	Articulation	Interacting with others, verbally or otherwise (with no other obvious activity)
B	Borderline	Being socially involved, but passively
C	Cool	Being socially uninvolved, withdrawn
D	Distress	Unattended distress
E	Expression	Engaging in an expressive or creative activity
F	Food	Eating, drinking
G	Games	Participating in a game
H	Handicraft	Participating in a craft activity
I	Intellectual	Activity prioritising the use of intellectual abilities
J	Joints	Participating in exercise or physical sports
K	Kum and go	Independent walking, standing or wheelchair moving
L	Labour	Performing work or work-like activity
M	Media	Engaging with media
N	Nod, land of	Sleeping, dozing
O	Own care	Independently engaging in self-care
P	Physical care	Receiving practical, physical or personal care
R	Religion	Participating in a religious activity
S	Sex	Activity related to explicit sexual expression
T	Timalation	Direct engagement of the senses
U	Unresponded to	Communicating without receiving a response
W	Withstanding	Repetitive self-stimulation
Y	Yourself	Talking to oneself, or to an imaginary person
Z	Zero option	Behaviours that fit no existing category

Scale of well-being and ill-being

+5   Exceptional well-being – it is hard to envisage anything better; very high levels of engagement, self-expression, social interaction

+3   Considerable signs of well-being; for example in engagement, interaction interaction or initiation of social contact

+1   Coping adequately with present situation; some contact with others; no signs of ill-being observable

-1   Slight ill-being visible; for example boredom, restlessness or frustration

-3   Considerable ill-being; for example sadness, fear or sustained anger; moving deeper into apathy and withdrawal

-5   Extremes of apathy, withdrawal, rage, grief or despair

Operational rules for DCM coding
When the participant engages successively in different types of behaviour within the same five minute period, the following rules apply:

Rule 1
The order of precedence when assigning behaviour category codes is:
1.   Type 1 categories (A E F G H I J M O P R S T X)
2.   K
3.   Type 2 categories (BCDUWY)
4.   N

Examples:
A participant is finishing his lunch. For about 2 minutes of the time frame, he is still eating and for the rest of it he is sitting and observing. Code this as F, not B.

A participant is sitting down in a withdrawn state, for part of a time frame and then begins to walk around. Code this as K, not C.

Rule 2
When 2 or more behaviours of the same type occur during the same 5-minute period, record the category engaged in most of the time.

Examples:
A participant is receiving physical care for about 4 minutes of a time frame, and is watching television for about 1 minute. Code this as P, not M.

A participant spends about 1 minute of a time frame tidying his clothing and about 4 minutes having a chat. Code this as A, not O.

Rule 3
When 2 or more behaviours of the same type occur for roughly the same amount of time, record the category that has the more extreme WIB value. When considering which WIB value is the more extreme, disregard whether it is a positive or a negative number.

Example.
In the first few minutes, a participant is eating and appears to be in a state of severe ill-being. In the latter few minutes she is leafing through a newspaper, apparently without distress. Code this as F-3 or F-5, not M+1.

Rule 4
When a participant is engaging in 2 or more behaviours of the same type for roughly the same amount of time, and which have the same WIB value (regardless of whether it is positive or negative), record the behaviour which occurred during the latter part of the 5 minute period.

Example:
A participant is engaging in an activity codable as H+1 for the first half of the time frame and an activity codable as P+1 for the second half. Code this as P+1, not H+1.

Staff feedback summary for ward 1

Here are a few of the ideas which guide my work with people with dementia which I would like you to think about.

I work with **people** with dementia, not people with **dementia**.

If we view dementia as a disability rather than a tragedy, it encourages us to look for potential in people instead of assuming inevitable decline.

Everything people with dementia do and say is potentially meaningful and therefore important.

I try to get to know the person with dementia: their life history; their likes and dislikes; what their mannerisms mean and their past and present relationships. This means that I can interact with them more fully. It also means that I can understand more fully their own views and experiences. I recognise the importance of occupation and activity in maintaining well-being.

This is **Person Centred Care** and this is what we should all strive for in our work with people with dementia.

While I cannot tell you my results, as I don't know them myself, I can tell you what I have observed in my time here which might be helpful to you in caring for your patients.
- Very good standard of physical care, which is important in maintaining well-being.
- Lots of lovely warm interaction between patients and staff, which is very important for maintaining well-being.
- Trips to the café, which help to bring some normality to their lives.
- You allowed patients choice, which helps to maintain some dignity: milk or juice at mealtimes.
- Some staff organised games/activities for the patients: excellent!

I also noticed some areas where a small change in practice would improve well-being.
- Banging doors are disruptive and make people jump.
- Some patients miss out on warm interaction and spend long periods alone.
- When it is quiet, staff tend to sit and chat together. This means that the patients are left to their own devices which is not always good.
- Sometimes the position of the person with dementia is over ruled and this has caused a drop in well-being.

I very much enjoyed my time on your ward and am grateful to you all for making me feel so welcome. Thank you.

Fiona Kelly.

Staff feedback summary for ward 2

Here are a few of the ideas which guide my work with people with dementia which I would like you to think about.

I work with **people** with dementia, not people with **dementia**.

If we view dementia as a disability rather than a tragedy, it encourages us to look for potential in people instead of assuming inevitable decline. Everything people with dementia do and say is potentially meaningful and therefore important.

I try to get to know the person with dementia: their life histories, their likes and dislikes, what their mannerisms mean and their past and present relationships. This means that I can interact with them more fully. It also means that I can understand more fully their own views and experiences.I recognise the importance of occupation and interaction in maintaining well-being.

While I cannot tell you my results, I can tell you what I have observed in my time here which might be helpful to you in caring for your patients.

- Staff carried out a very good standard of physical care which is important for maintaining well-being.
- Staff engaged in some warm and caring interactions with the women which is also very important for well-being.

I also noticed some areas where a small change in practice might improve the well-being of the women.

- Much of the interaction between staff and the women was task-orientated which meant that the interactions were brief and functional.
- Some patients missed out on warm interactions and spent a lot of their time alone.
- There were times when the emotional or social needs of people went un-noticed.
- There were times when staff fed people rather than allowing them to feed themselves.

I would like you to think about these three points:

- Try to make sure that every patient has some meaningful interaction with a member of staff regularly throughout the day. They do not have to be long interactions: you could look at a book or a magazine and reminisce, you could have a chat as you both walk along the corridor or you could spend a few minutes together admiring the fish.
- Try to allow the women to do as much for themselves as they can, particularly at mealtimes, even if it is a bit messy.
- If you can, take the opportunity to join the occupational therapy staff in their activity sessions. You will have fun, you will see the women in a different light and it will also give you something to talk about with them during the day.

I very much enjoyed my time on your ward and am grateful to you all for making me feel so welcome. Thank you, Fiona Kelly.

Staff feedback summary for ward 3

Here are a few of the ideas which guide my work with people with dementia which I would like you to think about.

I work with **people** with dementia, not people with **dementia**.

If we view dementia as a disability rather than a tragedy, it encourages us to look for potential in people instead of assuming inevitable decline.

Everything people with dementia do and say is potentially meaningful and therefore important.

I try to get to know the person with dementia: their life histories; their likes and dislikes; what their mannerisms mean and their past and present relationships. This means that I can interact with them more fully. It also means that I can understand more fully their own views and experiences.

I recognise the importance of occupation and activity in maintaining well-being.

This is **Person Centred Care** and this is what we should all strive for in our work with people with dementia.

While I cannot tell you my results yet, I can tell you what I have observed in my time here, which might be helpful to you in caring for your patients.

- Staff carried out good standard of physical care which is important for maintaining well-being.
- I observed some caring interactions between the staff and the men.

I also noticed some areas where a small change in practice might improve the well-being of the men.
- Most of the interactions between staff and the men were task and time-oriented which meant that the interactions were brief and functional.
- Once the tasks were complete, the men were mainly left alone with no occupational or social provision. This often resulted in boredom, apathy, restlessness or frustration.
- Staff often took over tasks that the men could either do themselves or do with help: feeding or unwrapping biscuit bars.
- Staff often walked too quickly with some of the men, which meant that the men were pulled along instead of being able to walk at their own pace. Staff seldom returned with the men to the seat they had taken them from, particularly at toilet and meal times.

I would like you to think about these three points:
- Try to make sure that every man has some meaningful interaction with a member of staff regularly throughout the day. They do not have to be long interactions: you could look at a book or a magazine and reminisce or you could have a chat as you both walk along the corridor.
- Try to allow the men to do as much for themselves as they can, even if it is a bit messy or a bit slow.
- If you can, take the opportunity to join the occupational therapy staff in their activity sessions. You will have fun, you will see the men in a different light and it will also give you something to talk about with them during the day.

I enjoyed my time on the ward and am grateful to you all for making me feel welcome. Thank you.

Fiona Kelly.

Individual Care Summary

Place: Ward 2   **Name: Brenda**
Date: 22/09/05   **Mapping period: 12.10-18.10**

WIB value profile

WIB value	-5	-3	-1	+1	+3	+5
% of time	0	0	20	80	0	0

Main behaviour categories, with percentage of time

BBC	K	W	P	O	X	
% of time	61	22	12	2	2	

Key categories not used at all: A,E,F,G,H,I,J,L   Individual WIB score: +0.6

Comments on care and quality of life:
Brenda has walked a lot today and some of the time she has been in ill-being. She can become disengaged while walking and this is not very good. There were no occasions when someone tried to engage with her for any length of time and this added to her isolation.

Comments on personal detractions:
While there were no individual personal detractors noted, this was mainly because there was such little interaction between the staff and Brenda. A general personal detractor is that of ignoring: ignoring the fact that Brenda has walked on her own for a long time: in isolation and sometimes in ill-being. Brenda was fed by staff and this disempowers her and denies her the opportunity to do something for herself.

General comments:
Meal times are a good opportunity to engage with Brenda, and they also allow her to do something for herself, even if it is picking up her food with her fingers. She does seem to enjoy eating with her fingers. It might be possible to order finger foods for her occasionally. It would also be good to see staff walking with Brenda occasionally to keep her company. She seems to like looking at the fish, this would be a good way of engaging with her.

John's Positive Event Record.   Place: Ward 3

Date: 18/10/05
Approximate time: 16.35
Participant(s) involved: John and an agency staff

Description of event:
John had been sitting on the couch looking at the television. He spotted something that interested him and nudged the agency staff who was sitting beside him chatting to another man. The agency staff leaned over to listen to what John was saying and he responded to John. The agency staff then noticed the skin flap on John's hand and spoke to him in a concerned manner about how he had sustained the injury.

Significance:
This was the longest interaction between John and any member of staff noted during the map. The event was significant in that the member of staff recognised John's attempts to communicate and he responded with kindness and interest. When he noticed the injury to John's hand he also showed sympathy and concern for him. The member of staff recognised John as a person with communicative needs and also as a sentient person.
…………………………………………………………………….....................

Date: 25/10/05
Approximate time: 14.00-15.00
Participant(s) involved: John and occupational therapy staff

Description of event:
John took part in the creative session, supported by the art therapist and occupational therapist. He spent the entire time concentrating hard and painting on Perspex.

Significance:
During the session, John worked hard and he seemed relaxed and content. Here, positive person work was seen in the collaboration between John and the art therapist and celebration at his effort and the work he produced. Following the session he was alert, his eyes were bright and he made enthusiastic efforts to communicate, both verbally and visually.
……………………………………………………………………………………….

Date: 25/10/05
Approximate time: 16.50
Participant(s) involved: John and an agency member of staff

Description of event:
Tea was over and the member of staff came in and was chatting with some of the men. John was sitting quietly. Suddenly he started talking and gesticulating enthusiastically and, although the member of staff could not follow everything John was saying, she listened intently and responded positively to him.

Significance:
This event was significant because the agency member of staff recognised he had something important to say and by listening intently and trying to follow what he was saying, she encouraged him to continue to communicate: recognition, validation.

(Indented text record my reflections)

Ward 3. Tuesday 11th October 2005.

I arrive in at 11.00am, later because I had stuff to do earlier. I say hello to people as I walk up the corridor to put my stuff away. The staff nurse who is on today is chatty and I think I like him. He tells me that he has only been here a few months. He has always worked in the acute psychiatry wards and this is his first venture into old age. He says he knows little about old people and about dementia.

John is walking back from the bedroom end of the corridor. When I say hello to him, he smiles brightly and takes my hand and leads me up and down the corridor. We walk up and down, up and down, and he is breathless but does not want to rest. As we walk towards the smoking room I try to guide him in so that he can sit and rest for a bit, but he pulls on my hand and veers me past the door.
        He has exercised a choice here and I respect it,

So we continue to walk up and down the corridor. We end up in the sitting room, and now I really want him to sit and rest because his steps are shuffly and he is breathless. I scan the books on the cabinet for something interesting and spot a golf book. I stretch over for it and show it to John. He immediately reads the author's name: Peter Allis and I ask him if he recognises the name; "Oh yes" he replies. He wants to walk again, but this time as we approach the smoking room, he enters it and we sit on a couch and he looks at the book. He concentrates on the text, running his finger over the list of players and I name some out and ask him if he remembers them. He does. After about 10 minutes he stands up: "Are you right?" he asks and I stand up and off we go again. The book is quite big and maybe he feels it heavy, for he asks me to mind it. I take it from him and hold onto it for him. He is tired now, and when we reach the chairs round the corner at the end of the corridor, he sits down. I hand him back the book and he opens it, this time onto a page that has tables of years and scores. He focuses on this, and on ones on subsequent pages until lunch time. I escort him into the smoking room for his lunch, and while he waits, he continues to look through the book. A care assistant serves lunch, but John is more interested in looking through the book than in eating. The care assistant brusquely takes the book from him and moves it out of reach into the middle of the table. John starts to eat.

I haven't seen much of the other men, except in passing, as I have walked up and down with John and looked at the book with him for most of the morning. William is at the dining table, looking a bit fed up. He gives me a half-hearted greeting. The other two men here are not looking happy either. I stay with them, but the care assistant is bustling and I feel I am in her way. I wander off.

In the sitting room, a student nurse is feeding a man. He is very quiet and I have never spoken to him. But when I squat down beside him he smiles at me. I am taken aback and am sorry that I have let a week go by and not tried to engage

with him. The student is chatty so I stay with her. She is wondering whether she should work here as a staff nurse. She says she is not sure whether she could cope with the bullying. I ask her is it the staff bullying the men or each other: "Both" she replies, except the bullying among the staff is the worst. She tells me that there are staff in the rest of the hospital who refuse to work here because they know they will be bullied by the staff here.

> *Well, I've already heard this, but I hadn't realised it was because of bullying. Now I remember the time I saw the two care assistants shout at the charge nurse, and I remember the discomfort on the faces of some of the agency staff.*

I spot Charlie sitting on the couch and go over to say hello to him, he gives me a lovely smile and I remind him of our chat about his cat yesterday. He responds but I cannot make out what he is saying. He hops up and walks away. The student nurse guides John over to a chair, but he does not settle. I find his book for him and give it to him. He sits and looks at it for a short while before getting up and walking away.

Kevin is sitting by himself. I go and say hello. He looks at me, gives a little smile, says something quietly that I cannot hear or understand. But as he talks, his tone is wistful and he looks around him glumly. As I sit with him, he drops off to sleep.

I wander off, up to the end of the corridor. I meet X (one of the non-participants who has become attached to me) coming towards me. Such a lovely big smile. His brace has come off and he is struggling to fix it, I offer to help him and he allows me to. I sit beside him and we smile. I chat and gesticulate to him and he is responsive. He puts his head on my arm and we sit like this for a while. Then he sits up and starts to sing: "daisy daisy…" and I join in and we sing it several times together. He tells me he loves me: "love at first sight" he says. A care assistant comes up to us and tells me he's deaf, then he shouts in each ear in turn: "how's your hearing?" "eh?" replies X.

Shortly after, I wave goodbye to X and wander into the sitting room. All is quiet, no staff anywhere, the television is on. Paul is sitting alone, I try to engage with him but he is not keen so I leave him be. A physiotherapist comes to take William down to the physio gym. I sit. Men are sleeping, sitting, walking, the tv is on loudly.

After half an hour, William returns. He goes to sit on the couch in front of the television. A children's programme is on loudly. I go and sit with him. He is puffed but is satisfied with himself. He describes the exercises he did and says that he is getting better. He is tired but bright. A staff nurse comes over and suggests that the station is turned over. He finds snooker, William is pleased. He says he likes snooker, he settles down to watch, soon his eyes begin to droop. I leave him to rest.

Charlie is sitting in his usual spot at the end of the corridor. I sit beside him and try to engage with him. He becomes weepy: "I don't like it here" and "I'm lonely".

I tell him that I could sit with him and keep him company for a bit, he says "Aye", looking at me. He tries to say something, his speech is fast and blurred, the left side of his face is flabby and I can't make out what he is saying. I say I'm sorry that I can't make it out, but I sit with him anyway.

I can hear staff talking in the laundry, their talk is loud and cross sounding, there must be about five of them and it sounds like they are giving out about something/someone. The charge nurse is not on, the atmosphere is heavy with bitter talk.

Although there are lots of staff on, there is no one in the sitting room. The men are sitting, walking or sleeping. I wander out into the corridor and it is busy out here. There are about five care assistants tidying out a room: hoists in the corridor, mattresses, mops, hustle and bustle, and in the middle, some of the men. One of the men is standing facing a locked door, a care assistant is in a hurry to enter, he sidles past the man, opens the door, squeezes through and closes the door loudly, all while the man is standing facing the door.

Kevin's wife is in. I introduce myself to her and we chat. She is worried about Kevin, he has been very sleepy today and does not respond to her attempts to wake him up. She tells me that he has deteriorated a lot recently. He eventually stirs and wakens up. His wife wants to take him along to the visitors' sitting room and she manages to persuade him to go with her. I help her to help him stand up but as we enter the corridor, he becomes irritable. Maybe the noise and activity in the corridor bothered him. He decides he is not walking any further but before I could establish what he wants, a care assistant takes over and talks impatiently to him, he is crosser now. Two care assistants bring him, unwillingly, into the smoking room and sit him on the couch. He sits grumpily and his wife sits beside him. She spends the next hour reading a paper.

It's a bit mad now. A patient is taking off his clothes. A care assistant is shouting at him to keep them on. John is standing at the front door. He has been here for about 2 hours and, on each occasion that I have tried to divert him away, he has refused. He is examining the wall rail, the paint work, and he seems content to continue to do this. There is a blind man who walks into people and things and several times I have rescued him and re-directed him so that he does not get hurt. Men are walking. Bill is watching snooker at the end of the corridor: "it passes the time" he says when I join him.

Eddie (OT) arrives to remind the staff that he intends to take some of the men to the social club this evening for the folk session. He would like some staff to accompany him. The session starts at 6.30 and they usually stay about an hour. The staff are arguing about who will go. No one wants to go: "It's not in my job description" says one care assistant. Eventually they settle on who will go, and he seems to have little choice in the matter.

The staff are brusque and noisy. I see them pulling the men along: to the toilet and later to the dining room. When the call for tea comes, Bill heads for the dining room where they all wait. Tea seems rushed. Charlie is eating slowly but a care assistant comes and feeds him, big spoonfuls of food. But there are also

attempts at kindness: staff hand out cake and chocolate to the men, but the cake is laid directly onto the table or shoved into the men's' mouths. Soon tea is over and the men are brought out again. John is being pulled by both hands even though he is well able to walk on his own. This pulling along causes him to stumble and have difficulty with his balance.

> *It is occurring to me that there is little individualised care here, all those who are not obviously independent walkers are pulled along by one or both hands. I have not yet seen a member of staff walk beside a man, they are always out front pulling the men along. I am also becoming aware that, today, there has been a group of men following me around and that wherever I sit, a group joins me.*

At 6pm, Eddie arrives to take some men to the social club. As only one member of staff is going with him, he can only take two men. He decides to take William and another man. I decide to go along too. What a good time! William is chatty, bright and alert and joins in the singing. We all have a good time.

> *I really cannot understand why the staff should resent coming along here especially seeing how the men blossom. What a pity that another care assistant could not have come along, then another man could have come and had a good time.*

I stay until 7.30 then go home.

Brenda's WIB Profile 22/09/05

Brenda's Behaviour Profile 22/09/05
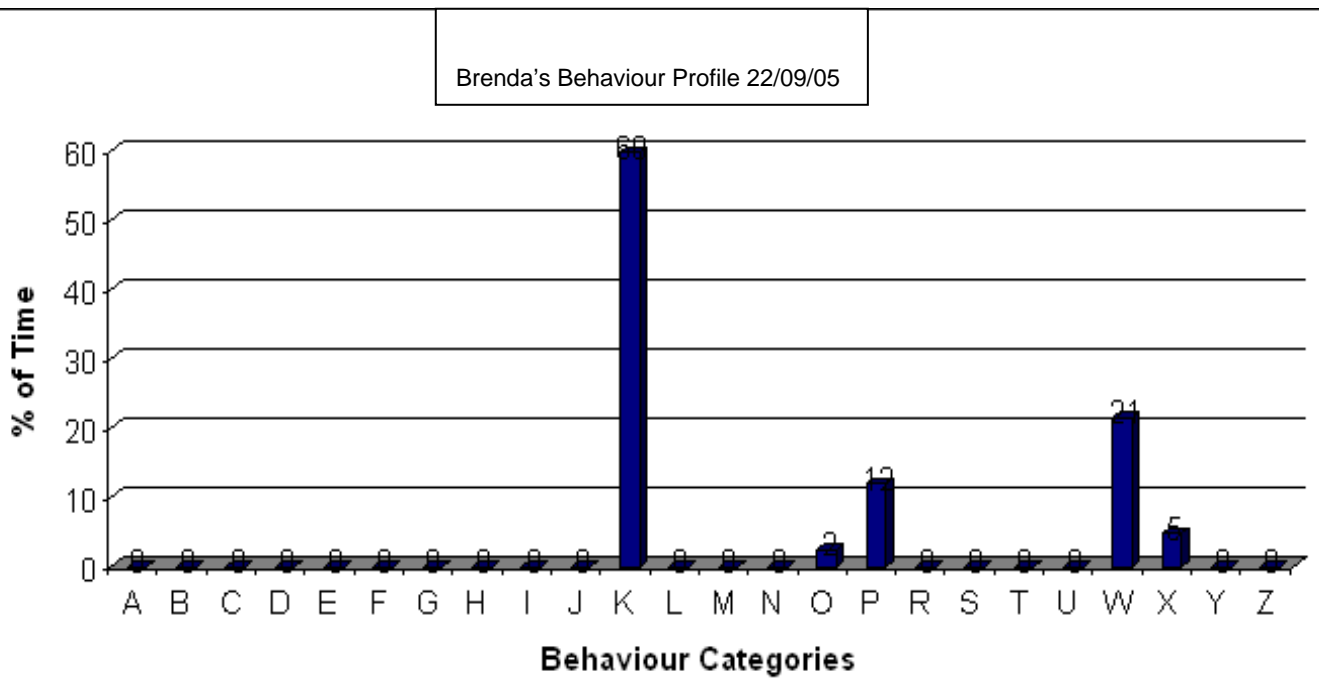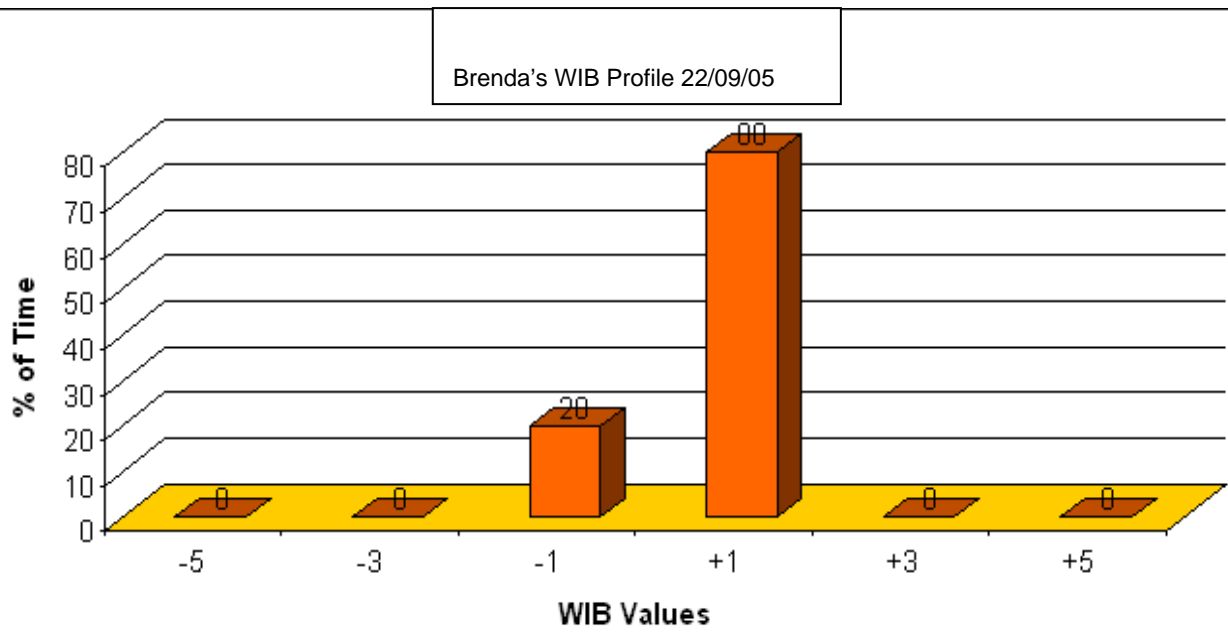
Appendix 9. Example of Group WIB and Behaviour Profile

Graphic representation of group WIB profile and group behaviour profile for ward 3. 22/11/05
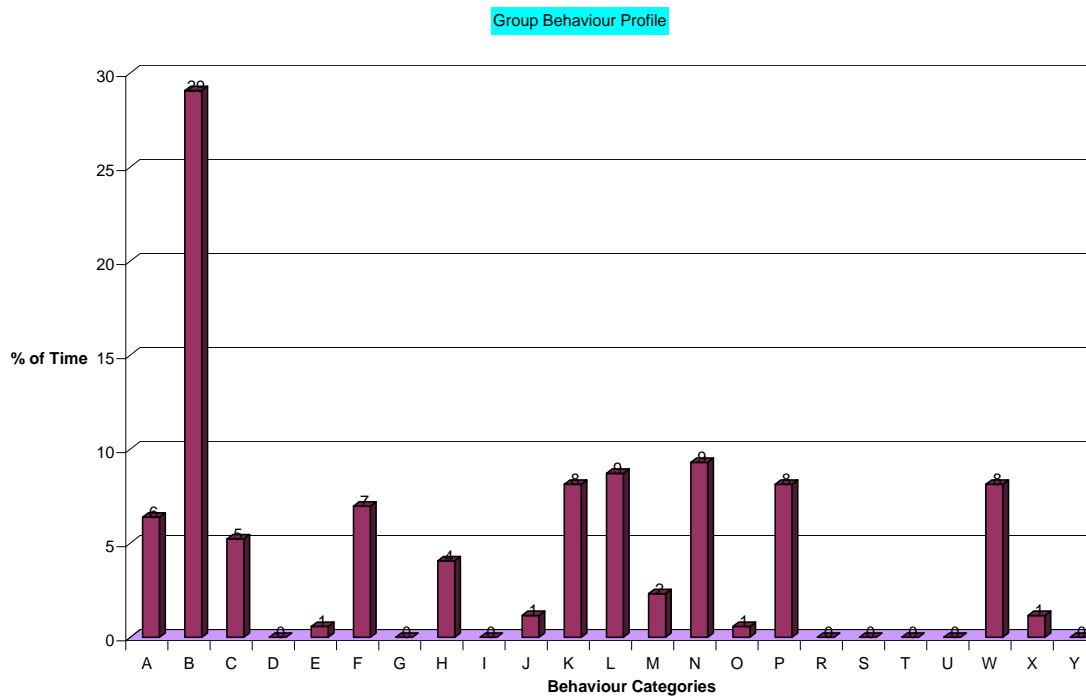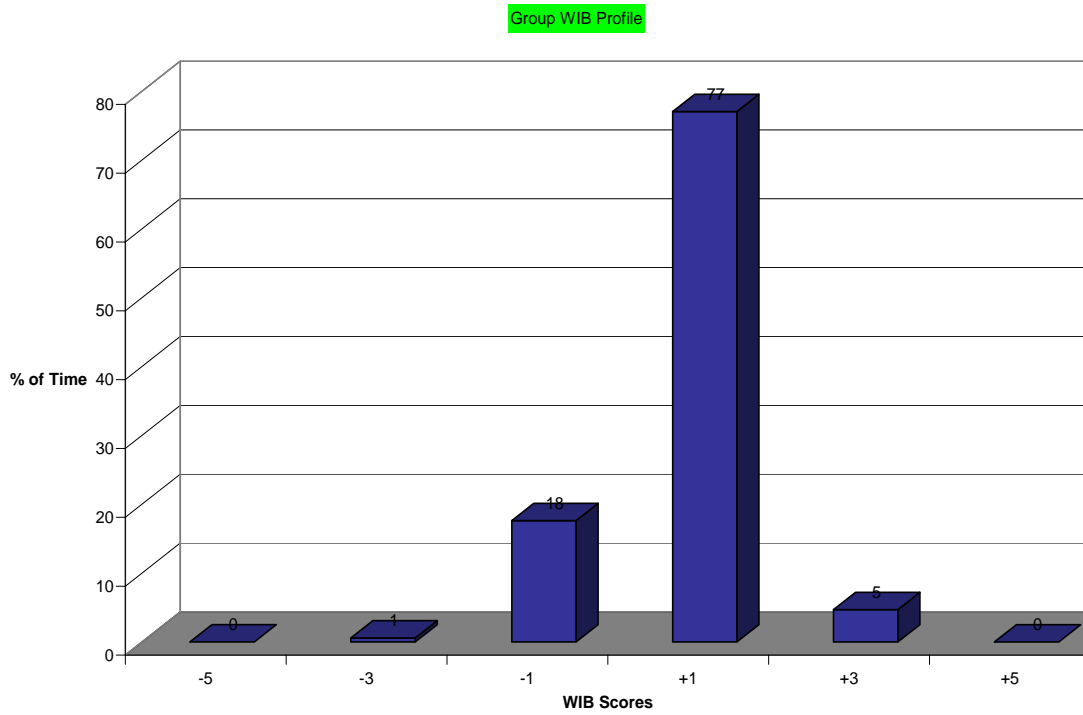
Group Care Summary

Place: Ward 3   Date: 22/11/05   Mapping period: 11.25-17.25
No. of persons mapped: 3   No. of paid staff: 6 1/2   No. of volunteers: 0

Individual WIB scores

Name	Score
John	+1.0
Charlie	+0.2
Paul	+0.8

Main behaviour categories, with percentage of time

BCC	B	L, N	K, P, W	F	A
% of time	29	9	8	7	6

Key categories not used at all: D,G,I,   Group WIB score: +0.7

Comments on positive events:
One positive event involved a member of the cleaning staff speaking kindly to Charlie. Another positive event involved John and the occupational therapy staff who worked with him at the creative session. In the afternoon, the occupational support worker noticed how bright he was and engaged with him warmly.

Comments on Personal detractions:
There were several general personal detractions today. Outpacing: where the men were pulled down the corridor and ignoring and withholding: where their social and psychological needs were unnoticed and unmet. There was one more serious one when Charlie was pushed backwards out of the bathroom when staff were attending to another man: intimidation, objectification, banishment.

General comments:
The men received good basic care, but no sustained, meaningful social interaction from the regular ward staff. This means that they spent long periods in isolation and sometimes in ill-being. Staff often have fairly long periods when they sit and chat to each other. It would be good if they could make sure that, during these quiet times, they spent some time interacting with the men in a meaningful and sustained way. This might improve their well-being and the overall well-being of the ward.

Appendix 11. NVivo7 codings

Name	**references**
Tree node\Abusive staff interactions\	
Punishment	2
Staff aggression	7
Tree node\After creative session\	
After creative session	32
Alert to environment	5
Finding occupation	32
Wanting to engage	18
Tree node\Barriers to good care?\	
Division of interaction	21
Lack of staff awareness	10
Low priority of dementia care	5
Sensitization	2
Tree node\Damaging staff interactions\	
Abandoned	1
Control	21
Ignoring	22
Staff intimidation	27
MSP. accusation	8
MSP. banishment	6
MSP. disempowerment	8
MSP. disruption	33
MSP. ignoring	13
MSP. imposition	6
MSP. infantilization	22
MSP. intimidation	8
MSP. invalidation	32
MSP. labelling	18
MSP. mockery	3
MSP. objectification	36
MSP. outpacing	33
MSP. stigmatization	3
MSP. treachery	1
MSP. withholding	15
Tree node\Description of ward\	
Description of ward	7
Poor ward environment	12
Ward atmosphere	13
Tree node\Expressions of Selfs 1-3\	
Exerting control/Self 2	11
Expressing pride/Self 2	10
Fragile expression of Self	110
Self 1	44
Self 2	78
Self 3	144
Self care/Self 2 or 3	21
Self-expression during creative session	11
Visual expression of Self	58
Tree node\Ill-being\	
Anxious behaviour	44
Expressing boredom	1

Patient sorrow	10
Physical discomfort	12

Tree node\Limited staff interactions\

Minimal care	16
Minimal staff interaction	87
Quick as possible	12
Task oriented care	190
Time oriented care	89

Tree node\Methods\

Debriefing	10
Ethnogrpahy. DCM	21
Participant consent	75
Staff consent	43
Trying to engage with participants	17
Video recording	21

Tree node\My role in research\

Difficulties, dilemmas, decisions	50
Impact of my presence	4
Impact on me	52
My interventions	66
My reactions	29
My sorrow	9

Tree node\No interaction\

No staff	21
No staff interaction	31
No support	1
Nothing happening	40
Staff group	40

Tree node\Occupational staff interactions\

Art therapist. Minimal interaction	3
Calm	3
Collaboration	3
Occupation. play	25
Offering, giving support	19
Praise	7
Recognition	18

Tree node\Participants\

Tree node\Participants' behaviours during creative sessions\

Concentration	15
Exercising choice	17
Expressing pleasure	19
Fun	2
Giving	1
Increasing self-confidence	10
Intellectual activity	35
Unexpected proficiency	15

Tree Node\Participants' reactions to damaging, negative interactions\

Defeat	7
Fear	2
Ill-being	68
Protest	13

Appendix 11. NVivo7 codings

Tree node\Participants' reactions to limiting or no staff interactions\

Forming attachments	2
Interactional destitution	98
Low mood	26
Passive recipient	1
Patient frustration	8
Reaching out to me	95
Reaching out to other patients	47
Seeking occupation	50
Seeking support	9

Tree node\Positive staff interactions\

Caring staff	4
Celebration	6
Providing occupation	13
Relaxation	4
Collaboration	1
Negotiation	4
Recognition	69
Validation	16

Tree node\Recognised.supported Self\

Recognised Self	253
Unrecognised Self	140
Supported Self	53
Unsupported Self	78

Tree node\Staff feedback sessions\

	Map 1	Map2	Map3	Map 4	Map 5
Nora	+1.0	Not mapped	+0.1	+1.1	+0.9
Florence	Not mapped	Not mapped	Not mapped	+1.0	+0.7
Edward	+1.0	+2.0	+0.9	+1.1	+1.0

Ward 1. WIB values. Nora and Florence did not participate in any creative sessions.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
3rd map		+0.8	+0.8	+1.0	+1.8	+1.0	+1.0	+0.9
4th map		+0.9	+1.0	+1.0	+1.2	+1.2	+1.2	+1.1

Ward 1. Edward's attendance at creative sessions.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Kate								+0.9
Brenda								+0.7
Mary								+1.1
Hannah								-0.1
Isabel								+0.9

Ward 2. First DCM: No creative session.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Kate								+0.8
Brenda								+0.8
Mary								+1.1
Hannah	+1.3	+0.8	+1.0	+2.6	+1.0	+1.0	+1.0	+1.4
Isabel	+1.3	+0.6	+1.0	+2.4	+2.2	+1.0	+1.6	+1.5

Ward 2. Second DCM: Hannah and Isabel at creative session.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Kate								+0.5
Brenda								+1.0
Mary	+1.1	Not mapped	+1.2	+2.7	+1.8	+1.2	+1.4	+1.3
Hannah	+0.6	+0.8	+0.8	+3.0	+1.7	+1.2	+1.3	+1.0
Isabel		+0.8	+0.6	+2.7	+0.8			+1.1

Ward 2. Third DCM: Isabel knitted in the morning, Mary and Hannah painted in the afternoon.

Appendix 12. Individual WIB values before, during and after creative sessions

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Kate								+0.5
Brenda								+0.9
Mary	+1.1	+1.0	+1.2	+2.5	+1.4	+1.0	+1.2	+1.4
Hannah	+1.2	+1.0	+1.2	+2.8	+1.2	+1.2	+1.2	+1.5
Isabel								+1.2

Ward 2. Fourth DCM: Mary and Hannah took part.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Kate								+0.4
Brenda								+0.6
Mary	+1.1	+1.2	+1.0	+2.4	+1.6	+1.0	+1.4	+1.3
Hannah	+0.6	+1.0	+0.8	+3.0	+0.5	+0.8	+0.7	+0.9
Isabel	+1.1	+1.2	+1.0	+2.4	+1.6	+1.0	+1.4	+1.4

Ward 2. Fifth DCM: Mary, Hannah and Isabel took part.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Kate								+0.8
Brenda								+0.6
Mary	+1.0	+1.0	+1.0	+2.3	+1.7	+1.2	+1.3	+1.3
Hannah	-1.2	-1.6	-0.8	+1.3	+0.1	+0.5	+0.3	-0.1
Isabel	+1.1	+1.2	+1.0	+2.3	+1.0	+1.0	+1.0	+1.2

Ward 2. Sixth DCM: Mary, Hannah and Isabel took part.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Bill	+1.0	+1.0	+1.0	+2.8	+1.4	+2.2	+1.6	+1.6
William	+1.0	+1.0	+1.0	+2.2	+1.4	+1.4	+1.4	+1.4
John								+1.0

Ward 3. First DCM: Bill and William participated in creative session

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Bill	+1.2	+0.8	+1.5	+2.5	+1.0	+1.0	+1.0	+1.4
William	+0.9	+1.0	+0.8	+2.3	+1.5	+1.2	+1.3	+1.3
John	+0.8	+0.7	+1.0	+3.0	+1.4	+1.2	+1.3	+1.5

Ward 3. Second DCM: Bill, William and John participated. John was not video recorded

Appendix 12. Individual WIB values before, during and after creative sessions

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Bill	+1.2	+0.8	+1.2	+3.0	Out	+3.0	+2.8	+1.8
William								+1.0
John	+0.4	+0.2	+0.8	+1.6	+1.4	+0.3	+0.8	+0.7
Charlie								+0.7

Ward 3. Third DCM: Bill and Ian participated. William and Charlie did not.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
Bill	+0.7	+0.8	+0.5	+2.3	+1.2	+1.0	+1.1	+1.1
William	+0.8	+0.3	+1.2	+3.0	+1.3	+1.0	+1.1	+1.3
John	+1.1	+1.2	+1.0	+1.8	+1.4	+1.4	+1.4	+1.3
Charlie								+0.4

Ward 3. Fourth DCM: Bill, William and John participated. Charlie did not.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
John	+0.8	+0.7	+1.0	+1.0	+1.4	+0.6	+1.0	+0.9
Charlie								+0.4
Paul								-0.1

Ward 3. Fifth DCM: John participated for 11 minutes. Charlie and Paul did not.

	Total time before session	2 hours before	1 hour before	Creative session	1st hour after	2nd hour after	Total time after	Overall WIB value
John	+0.8	+0.8	+0.8	+2.0	+1.5	+0.8	+1.2	+1.0
Charlie								+0.2
Paul								+0.8

Ward 3. Sixth DCM: John participated. Charlie and Paul did not.

UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

University of Stirling
Stirling   FK9 4LA Scotland

Telephone: +44 (0)1786 466340
Facsimile: +44 (0)1786 466333

Thank you for taking the time to read this information sheet.

I am a nurse who has worked with people with dementia for the past twelve years. I have become interested in how creative sessions might facilitate communication in people with dementia and how this might enable them to maintain a sense of identity. I am now exploring this in my Ph.D. studies.

I would like to seek your consent to video record each participant over a four-week period as they take part in the creative sessions. I will be studying whether and in what ways creative sessions might facilitate communication and whether, through the opportunity for communication, they can express different aspects of their identity. I will also be exploring the interactions that occur within the creative session and exploring the actual process of creating.

I plan to use a small digital camera, which will be placed in as unobtrusive a position as possible in order not to interfere with the sessions. I am aware that you might have reservations about being videoed and will be happy to talk with you about my previous research in which creative sessions were recorded. I would also like to reassure you that no-one but me and maybe my supervisors shall see the video-footage and that it will be stored in a locked filing cabinet at the University of Stirling. I would like to ask your permission to publish any relevant quotes in my thesis. I will ensure that all personal details will be changed so that you will not be recognised. I will be happy to show you any quotes I plan to use before I write the report. If you are not happy for me to use quotes I will respect your wishes. You can just not tick the box.

If you have any questions or concerns, please feel free to phone me. I can be contacted at **** *** **** or on my mobile: ***********.

Thank you,

Fiona Kelly RGN, BSc Psychology.

UNIVERSITY OF STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

University of Stirling
Stirling   FK9 4LA Scotland

Telephone: +44 (0)1786 466340
Facsimile: +44 (0)1786 466333

Please could you initial the boxes and sign below to indicate that you have read and understand this information sheet and that you are happy for me to video record the creative sessions.

I ………………………… have read and understand the information sheet. ☐

I have had the chance to ask questions and understand the answers. ☐

I am happy for Fiona to video-record the creative sessions. ☐

I am reassured that all information will be confidential and personal details will be kept anonymous. ☐

I am happy for Fiona to use relevant quotes in her report as long as they are kept anonymous. ☐

Name of artist/OT………………   Signature……………………. Date……….

Name of researcher……………..   Signature…………………….. Date………

1copy to artist, 1 copy to researcher.

UNIVERSITY OF STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

University of Stirling
Stirling   FK9 4LA Scotland

Telephone: +44 (0)1786 466340
Facsimile: +44 (0)1786 466333

Can creative sessions help people with dementia express their identity?

Thank you for taking the time to read this sheet.

I am a nurse and have worked with people with dementia for the past twelve years. I have become interested in how creative sessions might help people with dementia to maintain their sense of identity. I am now exploring this in my Ph.D. studies. I have been given ethical approval and permission from the hospital to carry out the research in this ward.

First of all, I would like to spend two weeks in the ward getting to know the patients and how they interact with others and how different types of interaction affect them. I would like to observe some of the interactions that take place in the ward between the patients with dementia and staff. I will be writing down what I observe in a notebook.

I want to reassure you that I will not be identifying individual staff. I am only interested in the interactions that occur in the daily lives of people with dementia.

I would like to meet with the staff on the ward and will be visiting the ward over the next week or so in order to meet with everyone, discuss the research with them and answer any questions.

I look forward to meeting you and to discussing my research with you.

If you are happy for me to spend the time on the ward observing and taking notes, I will ask you to sign a consent form.

If you have any questions or concerns, please feel free to phone me. I can be contacted on my mobile at ***********.
Thank you,

Fiona Kelly, RGN.

UNIVERSITY OF STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

Can creative sessions help people with dementia express their identity?

Please could you initial the boxes and sign below to indicate that you have read and understand this information sheet and that you give consent for Fiona to make observations of interactions between staff and patients with dementia in the ward.

I ………………………….have read and understand the information sheet. ☐

I have had the chance to ask questions. ☐

I understand that Fiona will be visiting the ward for two weeks to get to know the patients. ☐

I understand that Fiona will be observing and documenting the interactions between patients and staff. ☐

I understand that I will not be identified personally in any part of the research. ☐

I give my consent for observations to be made of interactions between myself and patients with dementia. ☐

Name……………………………   Signature……………………..   Date………

Name of Researcher………………..   Signature……………………..   Date……...

1 copy to staff member, 1 copy to researcher

UNIVERSITY OF STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

University of Stirling
Stirling   FK9 4LA Scotland

Telephone: +44 (0)1786 466340
Facsimile: +44 (0)1786 466333

Can creativity help people with dementia to communicate their feelings and needs?

All staff,

I am a nurse and a Ph.D. student and have been given permission to carry out research into the benefits for people with dementia of taking part in art sessions.

I am particularly interested in exploring whether art sessions help people with dementia to communicate their feelings and needs.

I plan to video record the art sessions but before I do so I will spend two weeks on the ward in order to get to know the patients, their next of kin and for them to get to know me.

I will also be observing and taking notes of the types of interaction they experience in the wards and during art sessions.

I will introduce myself each time I come onto the ward and will be happy to answer any questions.

*Please feel free to contact me if you have any questions on **** *** ****.*

I look forward to meeting with you on…… (early April 2005).

Fiona Kelly. RGN

UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

University of Stirling
Stirling   FK9 4LA Scotland

Telephone: +44 (0)1786 466340
Facsimile: +44 (0)1786 466333

Can creative sessions help people with dementia to communicate their feelings?

Thank you for taking the time to read this information sheet.

I am a nurse who has worked with people with dementia for the past twelve years and am now carrying out this Ph.D. study with the University of Stirling. I would like to explore the benefits for people with dementia of taking part in creative sessions.

I have had permission from your relative's consultant and the NHS to carry out this study. I would like to invite your relative to take part in this research. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear. I can be contacted at **** *** **** or on my mobile: ***********.

What is the purpose of this study?
This study will explore whether creative sessions such as painting and drawing can help people with dementia to express their feelings and intentions. I would like to video record the creative sessions, which your relative takes part in. I might also show him/her the film and ask him/her to comment on it. I will only do this if I feel that your relative is comfortable with taking part.

Why has my relative been chosen to take part in this study?
I am interested in exploring the experiences of people with dementia in long-term care settings and have identified that your relative is a long-term resident of this ward.

It is up to you to decide whether or not you wish your relative to take part. If you do decide that you are happy for him/her to take part I will give you this information sheet to keep and ask you to sign a consent form. You are free to withdraw consent at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your relative receives.

What will happen to my relative if she takes part?
I would like to spend two weeks on the ward so that your relative and myself can get to know each other. Then I would like to video record your relative over a four-week period in the art sessions in which he/she takes part. I do not plan to interfere in the sessions and will place the camera so that it does not cause discomfort or potential harm to your relative or any other participants. I might like to show your relative, with his/her consent, a film of him/her taking part in the art session. However, I will only ask permission if I feel that the footage is of a good enough quality and is pleasing to watch. I will not ask him/her to view it if I think it might cause upset or embarrassment.

What are the possible disadvantages and risks of taking part?
It is possible that your relative might become disturbed or distracted by the presence of the video-recorder. If this happens, I will stop recording immediately and comfort him/her. I will also allocate a staff nurse to monitor him/her and provide appropriate comfort if it is required.

What are the possible benefits of taking part?
There will be no immediate benefit to your relative in taking part in the video-recordings. However, he/she may enjoy seeing him/herself on the screen and may take pleasure in talking of his/her feelings on taking part in the art sessions. The information we get from this study should help us in understanding the experiences of other people with dementia.

What if something goes wrong?
I do not expect that an accident will happen. But, if your relative is harmed by taking part in the study, compensation from the university is possible. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, you can complain to the National Health Service Complaints Department.

Will information be kept confidential?
All information which is collected about your relative during the study will be kept strictly confidential. Any information about him/her which leaves the hospital will have his/her name and address removed so that he/she cannot be recognised from it. When writing up my findings I will make sure that details are changed so that he/she will not be recognised.

What will happen to the results of the study?
The results of this study will be published as my Ph.D. thesis in 2007. If you would like, I can send you a shorter version of my findings.

I would like to ask your consent to include any quotes from your relative that might illustrate my findings. Any quotes I would use would be kept anonymous: no personal details about your relative would be included. If you are not happy for me to use quotes, don't worry, just leave the box clear.

Please keep this sheet for future reference. If you are happy for your relative to take part, I will ask you to sign a consent form and to keep a copy of it for your reference. Please feel free to contact me at any time if you have any questions or concerns.

Thank you.

Fiona Kelly. RGN

UNIVERSITY OF STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

University of Stirling
Stirling   FK9 4LA Scotland

Telephone: +44 (0)1786 466340
Facsimile: +44 (0)1786 466333

Can creative sessions help people with dementia?

Researcher: Fiona Kelly

Please could you initial the boxes and sign below to indicate that you have read and understand this information sheet.

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐

I understand that my relative's participation is voluntary and that he/she is free to withdraw at any time, without giving any reason and without his/her medical care or legal rights being affected. ☐

I agree for my relative to take part in the above study. ☐

I understand that all information will be kept confidential and anonymous. ☐

I understand that at the end of the study a report will be written. ☐

I agree that quotes can be used on condition that my relative will not be recognised. ☐

Name of patient…………………………

Name of next of kin…………………. Signature…………………… Date……….

Name of researcher………………… Signature…………………… Date……….

1 copy for next of kin; 1 for researcher; 1 to be kept with hospital notes.

UNIVERSITY OF STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

University of Stirling
Stirling   FK9 4LA Scotland

Telephone: +44 (0)1786 466340
Facsimile: +44 (0)1786 466333

Thank you for reading this.

I am interested in studying how art sessions might help people to communicate their feelings.

I would like to ask you if I could video record the art sessions that you go to.

This will help me to find out how art might be helpful to people.

If you do not want me to video record you, you can just say so.

If you are happy for me to video record you I will show you the camera that I will use.

The camera will video record you while you are at the art sessions.

I will not show the film to anyone else, but I might ask you if I could show it to you later.

I would also like to ask you if I could quote some of your words when I write the results of the study.

If I do use quotes, I will change your name so that other people will not be able to identify you.

I will also ask your ………………….to make sure he/she is happy for you to take part in my study.

I will come back tomorrow and talk with you again in case you have any questions.

Thank you.

Fiona Kelly.