Psychosocial Care for People with Dementia in Long-Term Care:

The Use of Dementia Care Mapping

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Declaration

This thesis was carried out under the supervision of Amanda Gatherer. Additionally advise regarding research methods was sought from Jeremy Tudway, David Giles, Dawn Brooker and Stephen Joseph. Apart from the collaboration with the above people this thesis is my own work. I carried out all the data collection myself apart from the help received conducting the Dementia Care Mapping observations. This thesis has not been submitted for a degree at any other University. Ethical approval was given by the Worcestershire Local Research Ethics Committee (Appendix A1).

Submission of papers

The papers in this thesis have been prepared for submission to the following journals.

Literature review (Chapter 1) – Clinical Psychology Review (Appendix A2)

Main empirical paper (Chapter 2) - Ageing and Mental Health (Appendix A3)

Brief empirical paper (Chapter 3) - Dementia (Appendix A4)

Summary

A substantial proportion of people with dementia is cared for within long-term care settings. There is currently a greater recognition of the importance of providing for these individuals' psychosocial needs, and "person-centred care" has emerged as an important approach. Dementia Care Mapping (DCM) is a useful tool to evaluate and inform the provision of person-centred care. The aim of this work was to investigate the usefulness of DCM to improve the individual care provided to this group. The first paper provides an overview of psychosocial care for people with dementia in long-term care from a person-centred perspective. A review of the definitions of this type of care is provided and the models and approaches that attempt to guide psychosocial care provision are examined. The challenges of putting this care into practice and evaluating its effectiveness are also discussed. The second paper involves conducting a multiple baseline experimental design in order to investigate the effectiveness of DCM to inform the care plans for individuals with dementia in long-term care. The results from the study were inconclusive with regards to improvements in the patients. However, it is concluded that further investigations are warranted and recommendations are made. The aim of the third paper is to explore care staff's experience of DCM, as this method is very reliant on care staff accepting the changes to care delivery yet there is a paucity of research in this area. The results indicate that care staff perceive it to be a useful tool to inform their care practice but the method could be improved by including staff in this process. Finally, the process of carrying out this research, including the difficulties encountered, is reflected upon and the author's learning is discussed.

Chapter 1

A review of psychosocial care for people with dementia in long-term care from a person-centred perspective

Abstract

This article provides a review of psychosocial care for people with dementia in long-term care from a person-centred perspective. The models and approaches to guide the provision of psychosocial care are also discussed. The state of the current quality of care provided to this group is explored and the measurement tools that attempt to evaluate the quality of care are reviewed in brief. Conclusions are drawn regarding a potential role for clinical psychologists in providing training and support for the staff who care for people with dementia in long-term care. Additionally, suggestions are made regarding directions for future research.

Introduction

Recent reports indicate that a substantial proportion of people with dementia ends up being cared for in long-term care; namely nursing homes or long-stay wards (Marshall, 2001). For example, the Audit Commission in a recent report cited that 20% of people with dementia in the UK are in long-term care institutions (Audit Commission, 2000). This group on the whole represent those experiencing dementia that has progressed to a stage where their needs are at the most challenging. Their difficulties can include poor communication, behaviour problems, and needing a great deal of assistance with their physical care (Marshall, 2001).

The understanding and provision of care for people with dementia has changed dramatically over the last twenty years. Historically, the "biomedical" model has dominated this area, asserting that dementia is a progressive, debilitating disease caused by neurological impairment (Lyman, 1989). This viewpoint has resulted in "therapeutic nihilism" (Cohen, 1988), where the belief was held that nothing could be done for people with dementia apart from meet their physical needs (Sixsmith, Stilwell & Copeland, 1993). Treatment involved the use of medication to manage the behavioural disturbances common in people with dementia (Stokes, 1996). Moreover, the emphasis in research was placed on improving support for carers and searching for a cure (Woods, 2001).

It is now well established that it is not sufficient to consider dementia solely within this framework. The biomedical model has been criticised for being too simplistic since it fails to take into account both the impact of the care setting and the care-giving relationships on the experience of dementia (Kitwood, 1990; Lyman, 1989). It also neglects the individual's life history, personality and coping style, all of which may influence the way they present and cope with the experience (Kitwood, 1990). Hence, the focus has shifted onto the actual person with dementia; seeing them as a person coping with a disability as opposed to a victim lost to disease. Further, an understanding of the individual and their experience of dementia is considered important in order to provide care that is of any significance (Gillies, 2001).

Consequently, a more holistic approach to providing care is deemed necessary, addressing psychological and social factors as well as medical and physical needs (Kitwood, 1997a; Parker, 2001); in other words, psychosocial care. The approach that has come to represent this new culture of dementia care is referred to as "person-centred care" (Morton, 2000), and recent policies reflect this new way of thinking.

For example, the National Service Framework for older people has cited the provision of person-centred care as one of its standards of care (DoH, 2001).

The aim of this review is to explore in more detail what constitutes psychosocial care from a person-centred perspective for the people with dementia in long-term care. The first section focuses on how psychosocial care for people with dementia has been defined within the recent literature. The theoretical frameworks and supporting evidence on which these definitions are based is presented. The second part of the review addresses how psychosocial care can be provided to this group in practice. Thirdly, the actual quality of the care afforded to people with dementia in long-term care, and the challenge of determining the effectiveness of the care provision are considered briefly. Finally, conclusions are drawn regarding a potential role for clinical psychologists working in long-term care settings, and directions for future research.

Part 1 The meaning of psychosocial care for people with dementia

Definitions of psychosocial care

It is necessary to provide a definition of psychosocial care in order to understand how this type of care can be achieved in practice. In the recent literature, there has been a shift towards developing a "supportive" model of care that incorporates the individual's experience of dementia and involves helping them to cope (Finnema, Dröes, Ribbe & van Tilburg, 2000a). In line with this, Taft, Fazio, Seman and Stansell (1997) define a psychosocial model for dementia care as a "therapeutic model which validates the person with the illness, and builds on strengths and meets the person's needs" (p13), suggesting the focus in psychosocial care is on the individual needs of the person. They proceed to state that the caregiver's role is to "assess the individual's remaining strengths and abilities and provide a therapeutic milieu which supports personal identity and preserves personhood" (p14).

The recent definitions of psychosocial care are inherently based on an ideology that considers the needs of the individual first and foremost; an approach referred to as "person-centred care". There is no precise definition of person-centred care (Morton, 2000; Packer, 2000a). However, it involves treating the person with respect and providing care that is guided by the individual's experience (Stokes, 1996). It also emphasises the individual needs, preferences and remaining abilities and strengths of the person rather than their deficits (Morton, 2000; Woods, 2001).

Kitwood (1995a), in his definition of person-centred care, drew on the importance of maintaining the individual's "personhood". The concept of personhood has come to dominate psychosocial care approaches to dementia (Parker, 2001), and it has been defined as "a standing or status bestowed upon one human-being by others in the context of a relationship and social being" (Kitwood, 1997a, p8). Bell and McGregor (1995) expanded on this, stating that the task of care giving is to create environments where the person with dementia is valued.

It appears that as yet there is no agreed explanation of what constitutes psychosocial care; yet two common themes appear to be evident, and suggest that psychosocial care should:-

a. be guided by the *individual's experience of dementia*, helping to validate this experience and providing the support needed in order to cope with the consequences of dementia, and;

b. help to preserve the *individual's "sense-of-self"*, by treating them with dignity and respect, building on their individual strengths and abilities, and providing a supportive, therapeutic environment.

Achieving this is not easy and requires a good knowledge and understanding of the person.

Theoretical and empirical basis

Psychosocial care has been defined as supporting the individual through the experience of dementia and maintaining their sense-of-self. These requirements are discussed in more detail.

The experience of dementia

Dementia is characterised as an impairment of cognitive functioning and is also associated with behavioural disturbances, changes in affect, and functional abilities (Kasl-Godley & Gatz, 2000). These changes can be understood as a manifestation of the disease process, the response of the psychosocial environment (Kitwood, 1997a) and the way the individual perceives and copes with the experience of dementia (Bender & Cheston, 1997).

Kitwood (1990), in his influential theory of dementia, provided some insight into the impact of the psychosocial environment on the person with dementia. In brief, he argued the following. Dementia is a result of the interplay between neurological impairment and psychosocial factors. People with dementia receive negative reactions from others, a process he termed "malignant social psychology" (an example he cites is "stigmatisation"; that is treating the person as a diseased object). This leads to an exacerbation of the person's disabilities; that is, the psychosocial environment, and not just the cognitive impairment, contributes to the deterioration of the person with dementia. Kitwood's theory asserts that a supportive psychosocial environment was necessary to help the person cope with dementia.

The subjective experience of people with dementia has been largely ignored until fairly recently (Cotrell & Schulz, 1993; Kitwood, 1997b). However, accounts from people with dementia have provided some insight into what it may be like to have dementia, and demonstrate the individuality of the experience. McGowin's (1993) account offers some support for Kitwood (1990) as she described the unhelpful reactions of others. Additionally, she described an over-riding sense of fear and frustration, and also a lack of self worth, and guilt about her declining abilities. Goldsmith (1996) in his conversations with people with dementia reported that they feared becoming a burden, they wanted to be useful, and they required the reassurance of others. Further, Killick (1997) argues that dementia sufferers retain insight into their predicament and failing skills.

However, these accounts are based on the experiences of a small sample of people in the earlier stages of dementia and therefore may not be representational, particularly to individuals with more severe disabilities, as the needs and experience may change as the dementia progresses. It is more difficult to ascertain what it is like for people with more severe dementia, although second-hand accounts provide some insights. For example, Grant (1998) describes the experience of witnessing her mother going through dementia.

Bender and Cheston (1997) devised a comprehensive model of the subjective experience of dementia, which draws together the literature in this area. Firstly, they described the emotions likely to be experienced e.g. anxiety, depression, grief and despair. Secondly, they suggest that the person with dementia attempts to cope with the experience of cognitive impairment, and they reframe commonly reported phenomena experienced during dementia as coping responses e.g. denial, apathy and withdrawal. Finally, they state that the expression of emotion in the individual is dependent on their level of impairment, where people with more severe dementia respond more immediately and physically to their experience as they are less able to reflect. The likelihood of expressing emotion is also dependent on the receptiveness of the social context.

Furthermore, there is some indication that the need for security and safety is great in people with dementia, particularly as their cognitive impairment increases. For example, Bender and Wainright (1998), in their model attempting to explain the behaviours that occur in dementia, describe the individual's "safety system" being triggered as the disease progresses, which serves to alert the individual to threat. Along the same lines, Miesen (1992) has demonstrated an increasing need for security and attachment in those with severe dementia as they fail to make sense of the world around them and become increasingly insecure.

To summarise, these accounts and models suggest that the individuals with dementia have some insight into their predicament, at least in the earlier stages, and the experience can evoke a range of negative emotions. It is more difficult to determine what it might be like for those with more severe impairment however it appears that the feelings of anxiety and insecurity increase. Further, individuals actively seek to cope with what is happening to them and their responses may be more immediate and behaviourally demonstrated with more severe cognitive impairment. The way the person copes is influenced by the reaction of others, whereby a lack of support and understanding can contribute to the process of deterioration. Finally, individuals with dementia also confirm the need of reassurance and support of others to help them cope with the experience.

Maintaining the sense-of-self

At this point it is appropriate to review the evidence that suggests the individual's sense-of-self is threatened during the experience of dementia. The social constructionist perspective maintains that the dementia sufferer's sense-of-self is challenged (Cheston & Bender, 1999). Further, it stresses that the focus of care is to preserve personhood (i.e. a person's sense of identity), and if this is not maintained the person will degenerate into a vegetative state (Kitwood, 1990). Essentially, personhood consists of four global states, a sense of personal worth, a sense of agency, social confidence and hope (Kitwood & Bredin, 1992a). As mentioned previously, Kitwood (1990) stated that it was the "social psychology" surrounding the person with dementia that threatened their personhood. This approach emphasises that a person's sense-of-self is maintained through the relationship and interactions with the caregiver. In his theory of dementia care (Kitwood and Bredin, 1992a; Kitwood, 1993) Kitwood states that this relationship needs to be inherently therapeutic i.e. it should validate the person's experiences, provide them with space to express their emotions and facilitate their everyday actions.

Sabat and Harré (1992) provide some support for the perspective that personhood is challenged when a person experiences dementia. In their analysis of conversations with dementia sufferers they concluded that a person's sense-of-self could be lost in relation to interactions with others. Harris and Sterin (1999) also showed that people in the early stages of dementia report that their sense of personal identity is challenged and they have fewer opportunities to maintain a sense-of-self. Sabat (1994) demonstrated the reason for the importance of maintaining personhood by illustrating a difference in a person's behaviour, attitude and sense-of-self when in an environment that was judged to be supportive of personhood as compared to one which was not, with the former having a more positive influence on the individual. Similarly, Harris and Sterin (1999) presented two case studies that illustrated that psychosocial factors had a negative impact on self-identity.

Kasl-Godley and Gatz (2000) in their summary of the psychodynamic perspective of dementia also describe the struggle to maintain a sense-of-self in dementia. This is described as a weakening of the ego functioning, which results in reduced mastery over the environment and increased dependency. The person tries to cope with the consequences of dementia using defence mechanisms (e.g. denial and withdrawal), but this becomes increasingly difficult as the defence mechanisms fail and results in reactions such as regression, agitation, and isolation. Within this approach the support of others is deemed necessary to maintain a sense-of-self (Unterbach, 1994).

The problem with the studies cited, however, are that the sample sizes are small, and they involve people in the early stages of dementia, so again the results may not be representative to those more severely affected. In addition, Adams (1996) has criticised Kitwood's methodology in the development of his theories of dementia and dementia care, arguing a lack of empirical support, which puts the theories in some doubt.

Summary

As yet there is no clear definition of what is meant by good psychosocial care for people with dementia. For the purpose of this review, two broad themes of what care should try and achieve have been identified. The first emphasises the individual and emotional experience that the person goes through, and their need for understanding and support from others to help them cope with the cognitive, emotional and social impact of dementia. Secondly, the importance of maintaining the person's sense-of-self has been emphasised within the literature. However, the majority of the evidence is based on accounts and interviews with people with dementia in the earlier stages and it is more difficult to ascertain what the experience may be like for those more severely affected, although there are some suggestions that the individual becomes increasingly more anxious and insecure. There is also some evidence to suggest that the individual's sense-of-self is challenged by the reactions of others. However, the empirical support is weak and requires further investigation. The next part of the review will focus on how psychosocial care can be achieved in practice.

Part 2 The provision of psychosocial care for people with dementia

As suggested in the previous section, psychosocial care needs to maintain and enhance a person's sense-of-self, to try and understand what the person is experiencing, and to provide them with adequate support to deal with the consequences of dementia. In this section, some of the models of care and approaches that attempt to do this are discussed. It should be noted that this is not a definitive account, and rather aims to provide a representative view of the main models and approaches in this field.

Psychosocial models and approaches to dementia care

Models and approaches for understanding the experience of dementia and helping the person cope

Psychosocial models that attempt to consider the experience of the person with dementia and to help them cope with the consequences have been used to help guide care. Finnema et al (2000a) identified several psychosocial models used in dementia care and the two that have been applied to the care of people with dementia in long-term care are as follows. Dröes (1997) devised the “Adaptation-coping model”, which provides a framework for helping to understand the responses of the person with dementia. It views the individual as carrying out a number of adaptive tasks in order to help them adjust and cope, and the way they deal with these tasks is based on their personal, socio-environmental and physical health. Therefore, knowledge of these areas helps to direct care. Similarly, the “Progressively lowered stress threshold model” (Hall & Buckwalter, 1987) also attempts to understand what might be causing behaviour changes. This model aims to reduce the impact of perceived stressful events as it views the environment as having an increasingly stressful impact as the person with dementia deteriorates. Although Finnema et al (2000a) report that both these models have been used in care homes; there is no empirical support to demonstrate their effectiveness. Further, whilst they are useful in helping to understand the presentation of the person with dementia and the adjustments that might be made to the environment, they give little direction of how direct care should be provided.

Care approaches that use the therapeutic relationship and empathic listening to validate the individual’s emotional experience and to provide a supportive presence have been advocated e.g. Resolution Therapy (Stokes & Goudie, 1990). Similarly, Validation Therapy (Feil, 1992) attempts to support dementia sufferers by attempting to affirm their sense of reality. For more severe dementia, non-verbal validation techniques may include touch and “mirroring” (Achterberg, Kok & Salentijin, 1997). However, whilst these techniques have demonstrated some positive impact on people with dementia, they lack empirical support (Finnema, Dröes, Ribbe & van Tilburg, 2000b; Stokes, 1996). Additionally, an approach called Simulated Presence Therapy (SPT) (Woods & Ashley, 1995) has been designed to help reduce insecurity, and involves playing an audiotape made by the caregiver. Although initial investigations suggest that SPT reduces levels of anxiety and behavioural disturbances in people with dementia (e.g. Woods & Ashley, 1995) this approach requires further research evidence.

Behavioural disturbances are very common in people with dementia and are often perceived as the most stressful for carers (Donaldson, Tarrier & Burns, 1997). Such behaviour is viewed as a mechanism for helping the sufferer to cope with their predicament (Bender & Cheston, 1997) or as an unmet or poorly communicated need (Stokes, 1996), and some of the techniques already described appear to reduce indirectly behavioural disturbances. Additionally, "functional analysis" has been described as a sophisticated behavioural approach that involves an evaluation of the interrelationship of all the factors involved (i.e. neurobiological, past experiences, antecedents and the meaning of the behaviour to the individual). However, as yet there is only a small amount of research evidence to support the use of this approach (e.g. Moniz-Cook, Stokes & Agar, in press)

Hence, there are a limited number of models to guide the treatment for people with dementia in long-term care. Those available have not been empirically tested and are not based on theories specific to people with dementia. There is a plethora of techniques aimed to help the individuals cope with the consequences of the experience but, although they suggest some promise, there is limited research evidence to demonstrate their effectiveness.

Models and approaches for helping the person maintain a sense-of-self

Psychosocial models that aim to provide a framework to help the provision of care that maintains a sense-of-self have been developed. Taft et al (1997) constructed a psychosocial model of dementia care, which identified both psychological and social interventions that support personhood. Psychological approaches include taking the perspective of the individual with dementia, being responsive and offering choices. Social approaches include supportive touch and providing activities. Another model that provides a framework for supporting self-identity was proposed by Unterbach (1994), and suggestions include encouraging stimulation, the use of touch and positive relationships. However, the problem with these models is that they are not guided by the experience of people with dementia and they rely on the reports of caregivers or the ideas of researchers. In addition, it is unclear whether they have been tested empirically within care settings, and both warrant further investigation.

Kitwood (1997b) described a 'cluster of psychosocial needs' which, if met, would ensure the maintenance of personhood. These needs are attachment, inclusion, occupation, comfort, and identity. Miesen (1992) provides some support for the need for attachment. Additionally, Harris and Sterin (1999), in their conversations with people with dementia, identified the core values of self-identity as meaningful productivity, autonomy, comfort, and security. However, there is little empirical support for these psychosocial needs and they appear to be mainly based on clinical experience, the descriptions of people with dementia and by the accounts of other writers in this field. Kitwood (1997a) also outlined ten types of positive interactions that could help to maintain personhood. These include recognition of the person (e.g. giving them eye contact), consulting the individual about their preferences (rather than making assumptions), and encouraging the person's initiative and skills.

Within these guidelines, Kitwood referred to the importance of "engaging the senses" of the individual, and there has been an increase in the recent literature on the use of multi-sensory stimulation with dementia sufferers (MacDonald, 2002). This approach is not solidly grounded in theory but is based on the assumption that we all require sensory stimulation and that people with dementia often live in environments that are sensory deprived (MacDonald, 2002). The approach can involve using a multi-sensory environment or incorporating sensory stimulation into the individual's day-to-day experience (Ellis & Thorn, 2000; MacDonald, 2002). The evidence of the effectiveness of this approach is mixed, with some studies reporting improvements (e.g. Baker, Bell, Assey, et al 1998), whereas other studies state that they provide no more benefit than offering the individual an activity (MacDonald, 2002).

Reminiscence has also been used to help affirm a sense-of-self, using aids to prompt past memories (Gibson, 1994). Bender and Cheston (1997) note that reminiscence allows the person to establish a positive sense of identity, which is different to the one given to them as a dementia sufferer. Bender, Baukham and Norris (1999) also outline ways that reminiscence can be adapted for people with more severe dementia. However, there is a lack of studies of reminiscence work with individuals experiencing dementia (Woods, 1999) and, although the studies suggest a positive impact on interaction, generalisation of the results is difficult due to methodological limitation of the studies (Finnema et al 2000b). Additionally, the construction of life-story books that helps staff to get to know the person with dementia have been advocated to help the dementia sufferer maintain a sense-of-self, and to make care-giving an easier task (Woods, Portnoy, Head & Jones, 1992). There is also a growing body of literature of psychotherapy with people with dementia (Bender & Cheston, 1997), which has been considered useful to help maintain identity. However, it is not deemed appropriate for individuals in the moderate to later stages of dementia (Kasl–Godley & Katz, 2000).

Thus, there are few models available to provide a framework to guide care that supports the sense-of-self of dementia sufferers, and although those that are available seem promising, they require empirical testing in care environments. Despite the use of psychosocial interventions indicating positive results, research studies are often beset with methodological problems such as small heterogeneous groups, and the absence of appropriate controls.

Empirical support for psychosocial care

Having discussed in the previous sections what constitutes psychosocial care and how this can be provided, some support for the use of psychosocial care will now be examined. This evidence is based on the views of caregivers and people with dementia, and also from studies that have evaluated the outcome of the introduction of aspects of psychosocial care in long-term care environments for dementia sufferers.

Ericson, Hellström, Lundh and Nolan (2001) reported that carers of dementia sufferers viewed important aspects of care as a familiar environment, stimulating and rewarding activities and an intimate knowledge of the person with dementia. Similarly, Morgan and Stewart (1997) demonstrated the importance of stimulation and activity, human contact and individualised care in their interviews with staff and family carers. These were perceived to have more of an impact on quality of life than physical care. However, in criticism of these studies, Brooker (1995) noted that the views of carers could not be taken as a proxy for the person actually in receipt of care.

Bowers, Fibich and Jacobson (2001) explored the quality of care in long-term care facilities from the point of view of the residents. The relationships with staff were viewed as important aspects of care, and poor quality care was deemed to involve being treated as "invisible" and "stupid". Similarly, Dabbs (1999) identified relationships with staff being important to people with dementia. However, these studies focused on older people in long-term care and individuals with mild dementia respectively, and may not be applicable to people with severe impairment.

There have been several studies that have attempted to demonstrate that providing more individualised care to address psychosocial needs has a positive impact on the patients. For example, Sixsmith et al (1993) reported that improvements were observed in cognitive and functional abilities, with a reduction in behavioural disturbances in supportive settings that promoted individualised care. Bell and McGregor (1995) observed that residents within specialist residential homes providing this type of care demonstrated some improvements, and Annerstedt, Gustafson and Nilsson (1993) showed that psychosocial stimulation and therapy had positive effects on emotional symptoms compared to traditional care. In further support, Ory (2000) noted that several studies have documented a positive impact on residents' behaviour and social interactions in special care units (e.g Dean, Briggs & Lindsay, 1993). However, the majority of these studies have methodological flaws, making it difficult to draw firm conclusions. For example, the results could be attributed to the differences in the populations between the control and experimental groups, and also the reliability of some of the outcome measures is questionable given they were based on the subjective reports of care staff.

Kitwood (1995b) reported that positive long-term change is possible in people with dementia (i.e. a restoration of qualities they previously had) if psychosocial care is provided. However, this small study was based on retrospective reports of caregivers using an instrument that had not been validated. Other studies have shown that even when a positive care environment is provided, this has no discernable positive impact on patients and, in some cases; they may even deteriorate (e.g. Wimo, Nelvig, Nelvig et al 1993).

From the above it can be seen that the evidence is mixed regarding the effectiveness of providing psychosocial care. Caregivers and people with mild dementia view psychosocial care as an important aspect of care. Additionally, some studies suggest that psychosocial care causes positive changes in people with dementia in long-term care settings. However, it is difficult to compare the studies as different aspects of psychosocial care were applied. Also the reliability of the outcome measures used was questionable. The lack of availability of such tools is one of the reasons it is difficult to determine the effectiveness of care approaches and interventions. Some of the difficulties in providing and evaluating the quality of care for people with dementia is considered in the following section.

Part 3 How well is psychosocial care being provided?

There have been substantial improvements in the quality of care provided for people in long-term care (Innes & Surr, 2001), and increasing support for the provision of psychosocial care by care providers (Kitwood & Benson, 1995). However, it appears that meeting the psychosocial needs and measuring the quality

of care continues to present a challenge (Innes & Surr, 2001) and these areas are discussed below in brief.

The quality of care for people with dementia in long-term care

There is evidence to suggest that the care for individuals with dementia in long-term care is "unacceptable" (Ballard, Fossey, Chithramohan et al, 2001) and that it continues to focus on physical needs whereas the psychosocial aspects of care are ignored in comparison (e.g. Innes & Surr, 2001). Bruce (2000) found in one nursing home that physical care was of the most importance, emotional care was carried out in passing and occupational support was conducted when staff had the time. There also continues to be widespread use of medication in dementia care (Thaker & Jones, 1997). Further, it has been argued medication is often utilised when a psychosocial intervention may be more appropriate (Hermann, Lanctôt & Naranjo, 1996). The National Standards for residential and nursing homes for older people also highlighted the need for a review and improvements of the standards of care in long-term care settings (DoH, 1999). As Scott (2001) stated succinctly " it's the day to day care that's failing people with dementia"(p1427).

There are several complex reasons for the poor provision of care. The society we live in has been described as being inherently ageist (Bythemay, 1995) and "hyper cognitive" (Post, 1995), placing little value on people with dementia. These attitudes have resulted in dementia sufferers being regarded as low on the political agenda, and hence there is a lack of provision for health care services (Innes, 2002). Consequently, people with dementia are often cared for in settings with limited resources, where some care staff hold ageist attitudes (Litern, 2001) and where little training and support is provided (Marshall, 2001).

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There is evidence to suggest that the care for individuals with dementia in long-term care is "unacceptable" (Ballard, Fossey, Chithramohan et al, 2001) and that it continues to focus on physical needs whereas the psychosocial aspects of care are ignored in comparison (e.g. Innes & Surr, 2001). Bruce (2000) found in one nursing home that physical care was of the most importance, emotional care was carried out in passing and occupational support was conducted when staff had the time. There also continues to be widespread use of medication in dementia care (Thaker & Jones, 1997). Further, it has been argued medication is often utilised when a psychosocial intervention may be more appropriate (Hermann, Lanctôt & Naranjo, 1996). The National Standards for residential and nursing homes for older people also highlighted the need for a review and improvements of the standards of care in long-term care settings (DoH, 1999). As Scott (2001) stated succinctly " it's the day to day care that's failing people with dementia"(p1427).

There are several complex reasons for the poor provision of care. The society we live in has been described as being inherently ageist (Bythemay, 1995) and "hyper cognitive" (Post, 1995), placing little value on people with dementia. These attitudes have resulted in dementia sufferers being regarded as low on the political agenda, and hence there is a lack of provision for health care services (Innes, 2002). Consequently, people with dementia are often cared for in settings with limited resources, where some care staff hold ageist attitudes (Litern, 2001) and where little training and support is provided (Marshall, 2001).

Innes (2002) argues that improvements in care provision are possible. She cites the changes in Scottish legislation as an example; the Scottish Executive (2001) plan to make long-term care needs for older people a priority for additional resources. The recent National Service Framework also shows some promise in that it plans to improve quality and decrease inequities in service provision across the UK (DoH, 2001). However, Innes (2002) states that such policies are yet to make their mark.

Challenges of assessing the quality of care

One of the major difficulties in the provision of psychosocial care is how to evaluate its effectiveness. The nature of dementia means it is often not possible to consult with dementia sufferers, particularly those with severe impairment. A potential way to overcome this problem is to ask carers to rate the outcome of the care, and there are assessment tools available that are carried out with carers in order to measure the affective experience of the individual with dementia. Greatorex (2001) noted that the majority of these tools measure the negative aspects of dementia (e.g. challenging behaviour and negative affect). This approach has also been criticised as it may not fully represent the experience of the person with dementia (Brooker, 1995). Alternatively, measuring the quality of care by direct observations of the individual within care settings has been carried out, and Brooker (1995) has published a comprehensive review of the measures available for this purpose. Brooker criticised the majority of these tools on the grounds that they only measure the behaviour, or level of activity, of the dementia sufferer, and concluded that, since there is no theory to suggest that the amount and the type of occupation indicate a good quality of care, these tools are inadequate for this purpose. Further, both the proxy assessment measures and the observational tools described, only measure the outcome of the care and not the quality of the actual care provided (Innes & Surr, 2001).

Dementia Care Mapping (DCM) is an observational tool that is based on Kitwood's theories of dementia and dementia care. It was designed for the purpose of evaluating the quality of care in formal care settings (Kitwood & Bredin 1992b; Bradford Dementia Group, 1997). This tool is an advance on the other measures described as it is grounded in theory, it evaluates the care process (i.e. the behaviour of the care staff towards people with dementia), and it measures the impact of the care on the dementia sufferer from their perspective. The latter is carried out by looking for behavioural indicators of "well-being" and "ill-being", as Kitwood argues that people with dementia are able to indicate clearly through their affective state whether they are having their needs met. DCM not only assesses and evaluates the care, but it also provides a theoretical framework for guiding the care to ensure that personhood is maintained. DCM is not without its criticisms, and it is not a substitute for the views of dementia sufferers (Brooker, 2002). However, currently it is considered the best tool to understand and evaluate the care from the perspective of the person with dementia (Audit Commission, 2000).

Summary

Although the care for people with dementia in long-term care has improved, and there is currently more acceptance that it is important to provide psychosocial care, it appears that its provision is not yet commonplace. This is mainly a result of ageist attitudes in our society, which have negatively impacted on the health care provision for people with dementia. Further, evaluating the quality of dementia care continues to present a challenge. The majority of measurement tools available determine the outcome of care but fail to evaluate the care process. Dementia Care Mapping emerges as a potentially useful tool for evaluating the quality of care as it takes into account both these areas. It also provides a useful evidence-based framework to direct the provision of care that addresses the psychosocial needs of the individuals.

In light of some of the issues raised in this review regarding the nature of providing psychosocial care and the lack of empirical support that exists, the last part of the review focuses on a potential role for clinical psychologists and areas for future research.

Part 4 Implications and Conclusions

Implications for clinical psychologists

Clinical psychologists are often not actively involved in providing psychological care for people with dementia in long-term care, and it is direct care staff that play a major role in meeting their care needs (Kramer & Smith, 2000). This review has drawn attention to potential areas where clinical psychologists could help staff provide care more effectively and these are discussed in turn.

Training

It has been highlighted that negative staff attitudes towards people with dementia exist in care settings. Care staff also receive little training and therefore they may be unaware of recent changes in approaches to dementia care (Marshall, 2001). Clinical psychologists could play a role in designing strategies for staff development to address some of these areas (e.g. improving staff attitudes and helping them understand and meet the needs of dementia sufferers) (Keough & Hueber, 2000). Studies that have attempted to assess the effectiveness of training for care staff are promising and suggest improvements in care practice, such as more helpful attitudes towards patients and increased engagement in activities and social interactions (e.g.

Litern, Woods, & Phair, 2000). It has also been suggested that care staff receive a lack of support from management in putting skills learnt during training into practice (Kramer & Smith, 2000). Therefore, clinical psychologists could also be involved in training management staff about the care needs of people with dementia. This could promote the development of mechanisms to encourage staff to carry out psychosocial as well as physical care.

Support and supervision

This review has indicated that the provision of psychosocial care could be emotionally draining for staff, and thus clinical psychologists could also provide support and supervision which is currently lacking in long-term care settings (Keady, 1996). It has been suggested that a lack of support can result in staff burnout, absence from work, and a high staff turnover (Keough & Huebner, 2000). Other research suggests that the levels of distress in care staff are no greater than in the general population (Woods, 1995). However, this may be because staff are not fully engaging in the task of caring and may be remaining emotionally detached (Woods, 1995), which is not conducive to providing psychosocial care. There is also some evidence that providing support groups to care staff results in staff being more likely to remain in their job (Wilner, 1993).

Packer (2000b) argued that care staff cannot be expected to deliver person-centred care if they are not themselves treated as valued individuals. Providing adequate training and support could be a step towards achieving this and clinical psychologists may have an important role to play.

Directions for future research

There has been a substantial growth in the research in this area, however this review has highlighted that further work is required. Research into the subjective world of the person with dementia would be beneficial as this provides valuable insights into the direction of care (Bender & Cheston, 1997). Such research is required particularly with those individuals with more severe impairment (Downs, 1997). Downs suggested employing the methods described by Kitwood (1997b), which includes interviewing dementia sufferers.

The psychosocial models and approaches described also warrant further research in order to provide evidence for their effectiveness in practice. The use of single case experimental designs may be of benefit, as this would take account of the variability between dementia sufferers (Woods, 1999). Further, it seems pertinent to continue to develop methods for evaluating the process and outcome of care in order to determine which aspects of care are beneficial. Additionally, given the paucity of resources often available in care settings for the elderly, research into applying psychosocial care within these limited resources maybe of use. This is summed up by a comment made by a care worker " There is plenty of information that tells us what we should be doing; I really need something or somebody to show me how to achieve all these things in my current working environment" (Packer, 2000a, p21)

Conclusions

This review has aimed to present an overview of psychosocial care for people with dementia in long-term care settings from a person-centred perspective. Providing this type of care is receiving more recognition, and it is viewed as being of increased importance to deliver quality dementia care. Psychosocial care involves supporting the person through the experience of dementia, helping them to cope with the consequences of this disease, and also maintaining their sense of identity as this may be threatened. This involves gaining an understanding of the experience of the person with dementia and developing a relationship that is inherently therapeutic. There are some models and approaches available that offer some direction for care workers, however these require more empirical support. Further, clinical psychologists could play an important role in providing the necessary training, support and supervision to the care staff that are responsible for the care of these individuals. This is often lacking and is of importance in order for care staff to be able to provide this type of care. Psychosocial care is not without its challenges since it is difficult to establish whether quality care is being delivered because of the limitations of the measurement tools available. Further, providing good dementia care continues to be low priority and is not yet commonplace. This raises the question whether such a high level of individualised care provision is possible within the existing care system and more resources may be necessary to make this happen.

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Chapter 2

The effectiveness of Dementia Care Mapping as a care-planning tool: An initial investigation

Abstract

Providing good quality care for people with dementia has become increasingly important, with Dementia Care Mapping (DCM) becoming the tool of choice to evaluate and inform care practices within formal care settings. The aim of this study was to investigate the use of Dementia Care Mapping (DCM) to inform individual care plans for people with dementia in long-term care, as there is a paucity of tools available in this area. A multiple baseline experimental design was carried out within an NHS long-term care setting. Care plans informed by DCM recommendations were implemented to the participants. Health-related quality of life and psychological well-being were used to measure the outcome of the care provision. The results of this study do not conclusively support the use of DCM as a care-planning tool. However, it is concluded that further investigation is warranted and recommendations are made for future research.

Introduction

Many people develop dementia, with the likelihood of this happening increasing with age (prevalence rates are approximately 5% for individuals over 65 years of age, rising to over 25% for persons over 85 years of age; Schindler & Cucio, 2000). A substantial proportion of these people end up being cared for in long-term care settings (Audit Commission, 2000). Although advances in pharmacological treatment for dementia continue, there is still no cure for dementia (Parker, 2001). Therefore, providing good quality care remains a high priority (Ory, 2000), and a person-centred approach to care is viewed as an important aspect towards achieving this (Kitwood & Benson, 1995).

Person-centred care involves trying to understand the experience of the person with dementia, providing individualised care that is tailored to support and meet their needs, and treating them with value and respect (Kitwood, 1995; Morton, 2000). It is based on the understanding that the experience of dementia is not only a result of the cognitive impairment but also a representation of the person's individual response and the reaction of the social context, with support from the latter being important to prevent psychological decline (Kitwood, 1997). There is a growing body of research literature to support the effectiveness of person-centred care in practice, which suggests that providing this type of care can have a positive impact on individuals with dementia compared to traditional approaches to care (e.g. Sixsmith, Stilwell & Copeland, 1993).

There is currently an absence of tools available to help care staff understand the experience of people with dementia and to guide care provision (Brooker 2002). Some tools exist that attempt to assess the quality of the care provided (e.g. the Patient Behaviour Observation Instrument; Bowie & Mountain, 1993). However, these are based on assessing how the person with dementia spends their time, and provide no indication about the how the individual with dementia perceives the care received (Brooker, 1995). The individual's affective state (i.e. psychological well-being) has emerged as an important way to understand the experience of the dementia sufferer (Lawton, 1997), as they are often unable to report on the care they are receiving, and tools exist to measure affective state (e.g. the Affect Rating Scale; Lawton, Perkinson, Vanhaitsma, et al, 1996). However, whilst these measures provide an indication of the person's well-being, they provide no indication of how the care is directly impacting on the individual (Innes & Surr, 2001). Further, there are some tools to help guide care-planning for people with dementia. For example, Little and Doherty (1996) reviewed measures that assess the needs and service provision of people with dementia. However, they are not based on the subjective experience of the dementia sufferer. Finnema, Dröes, Ribbe and Van Tilberg (2000) also described models to help direct care in long-term care that provide a framework to help understand the presentation of the person with dementia. However, these lack empirical support within care settings.

Dementia Care Mapping (Bradford Dementia Group, 1997; Kitwood & Bredin, 1992) emerges as a potentially useful tool as it is an observational method that attempts to evaluate the care provision from the perspective of the person with dementia (i.e. the method informs how the care is impacting on the individual's well-being; Innes & Surr, 2001). It also indicates in clear behavioural terms what is necessary to improve the care (Brooker, 1995; 2002) as it provides an evidence-based framework for informing the care practice of staff to ensure they are person-centred in their approach (more specific details of the Dementia Care Mapping method are provided later in this article). Therefore, Dementia Care Mapping (or DCM) may offer a useful framework to contribute to the care plans of dementia sufferers in long-term care. However, currently there is little empirical evidence to support this directly.

There is a growing body of published research to support the effectiveness of the DCM method in practice. For example, Brooker, Foster, Banner et al (1998) showed that DCM is an appropriate audit tool to measure the outcome of the care process in formal dementia care settings with improvements in the quality of care demonstrated. DCM has also been used as an outcome measure of care more generally (e.g. Innes & Surr, 2001). It has also been employed usefully to evaluate the effects of therapeutic interventions for people with dementia (e.g. Brooker & Duce, 2000). Brooker (2002) in her summary of DCM concluded that when the care setting is supportive of DCM, an increase in patient well-being, an increase in staff job satisfaction and a positive influence on staff practice, is achievable.

However, although DCM appears to be a valuable tool, it is not without its limitations and criticisms. The use of DCM to evaluate care environments takes a lot of organisational abilities (Bolton, Gee, Jackson, et al 2000). It also takes a significant amount of time to carry out the DCM observations. Greatorex (2001) argued that DCM has not been empirically scrutinised about the assumptions it makes regarding the nature and structure of well-being. Finally, the representation of the DCM data within the literature, when reporting the outcome of care, has been criticised for being misleading about the nature of the care environment (Edward & Fox, 2001; James, Lee, Sells & Allen, 2002).

The present study

The aim of the present study is to investigate the use of DCM as a tool to inform the care plans of people with dementia in long-term care with a view to improving the quality of care offered. The research was conducted using a multiple baseline experimental design. This design was used as DCM is relatively unproven in this area and because it allowed for the variability in presentation of people with dementia (Woods, 1999). Individuals with low well-being were identified (as measured by DCM) and their care plans were informed by the DCM recommendations. The changes to care were put into practise and their effect on the individuals' health-related quality of life and well-being was measured. DCM and the dimensions of well-being in people with advanced dementia reported by Volicier, Camberg and Hurley et al (1999) (i.e. happy-sad mood, calm-agitation, engagement-apathy) were used to measure the outcome of well-being. It was hypothesised that the use of DCM to inform the care plans would result in an increase in the well-being and quality of life of people with dementia in long-term care.

Method

Setting

The NHS Trust in which this study was conducted had introduced DCM to all of the care facilities for people with dementia. Many staff had been trained in the DCM method, and all of the care facilities for older people with dementia were evaluated annually using DCM. This study was conducted on an 18-bedded inpatient unit that provided continuing care for people with dementia. Typically, four staff members staffed the unit and the care provided met the physical care needs of patients with less time spent focusing on occupational or social needs.

Design

The single case experimental design used implemented a multiple baseline across the participants. This allowed for the individualised treatment plans that were necessary as a result of the variability between the individuals with dementia (Woods, 1999). This approach offered the additional benefit of providing a means to use the participants as controls to demonstrate the effect of the intervention, as withdrawal of the intervention was not possible (Long & Hollin, 1995). The dependent variables were the participants' health related quality of life and psychological well-being. The independent variables were the revised care plans informed by the DCM feedback. The participants all shared the same environmental conditions and one of the participants received no intervention, to measure for potential carryover effects (i.e. where the change in one participant's care influences care staff's behaviour towards the other participants).

Measures

The following outcome measures were conducted with care staff.

The Alzheimer Disease Related Quality of Life (ADRQL)(Rabins, Kasper, Kleinman et al, 1999) provides a measure of health related quality of life for people with Alzheimer's disease (Appendix B1). It consists of five domains: social interaction, awareness of self, feelings and mood, enjoyment of activities and response to surrounding, and is designed to measure change over a 2-week period. Initial investigations offer support for good internal consistency and validity (Gonzalez-Salvador, Lyketos, Baker et al, 2000).

The Cohen-Mansfield Agitation Inventory (CMAI) was used to measure the agitated-calm dimension of well-being (Cohen-Mansfield, Marx & Rosenthal, 1989, Appendix B2). This caregiver-rating questionnaire includes descriptions of twenty-nine agitated behaviours, each rated on a 7-point frequency scale. The CMAI was developed and standardised for use with an elderly population. Inter-rater agreement rates range from 0.88 - 0.92. Factor analysis suggests it is a valid tool for assessing agitated behaviour in an elderly residential population (Cohen-Mansfield, 1991).

The Depression Rating Scale (DRS)(Cohen-Mansfield, 1988) was used to measure the affect dimension of well-being (Appendix B3). It is a 6-item caregiver questionnaire designed for an elderly population and taps into two factors: sad affect and social functioning. Inter-rater agreement rates average 0.69 (Cohen-Mansfield, 1988).

The Pleasant Events Schedule-AD-short form (PES) (Teri & Logsdon, 1991) was used to measure the amount of time engaged in enjoyable activities (Appendix B4). It consists of twenty potential pleasant events in which people with Alzheimer's disease may engage. The scores include a rating of the frequency engaged in activities, an enjoyment rating and a frequency of enjoyable activities (a cross product of the other two scores). The questionnaire has demonstrated good reliability and validity (Logsdon & Teri, 1997).

Direct observations of the participants were also used as an outcome measure of well-being using Dementia Care Mapping (DCM).

DCM (Bradford Dementia Group, 1997) involves observing the person with dementia for five-minute successive time periods over a representative amount of time (e.g. six hours over one day). "Mappers" observe up to ten individuals, and, for each five-minute observation period, a behaviour category code (BCC) and a well-being value (WIB) are recorded. The BCC summarises what that person has been doing and is denoted by a letter, with twenty-six codes in total (e.g. *A* refers to an inter-personal interaction) (Appendix B5). The WIB is a number assigned from a six-point scale (*–5, -3, -1, +1, +3, +5*) to denote the degree of the person's well-being (+ve value) or ill-being (-ve value) (Appendix B6). A concordance coefficient of at least 0.8 is recommended in order to ensure good inter-rater reliability between the mappers. The DCM method also records the positive and negative care interactions (these were not used as outcome measures).

The data can be analysed in several ways. The individual WIB score is an aggregated score that represents the individual's average well-being during the observation period and can be interpreted from a standardised table (Appendix B7); the higher the score the better the well-being. The individual WIB value profile indicates the proportion of time spent in each band of the well-being scale. The BCC profile illustrates the amount of time spent in each behaviour category and highlights occupational needs. The results from DCM are fed back to the staff team and provide a basis to inform the care provision.

Participants

Participants were included if they:

i. Achieved a WIB score of 0.9 or less on DCM. This indicates that the care needs improvement (Appendix B7).

ii. Had received a diagnosis of dementia (obtained from the medical notes).

iii. Had similar levels of dependency. The survey version of the Clifton Assessment Procedures for the Elderly (CAPE) (Pattie & Gilleard, 1979) was used to assess the dependency level of each participant. This provides an index of physical dependency and cognitive impairment. Scores range between +12 and –12, the highest scores represent low dependency and vice versa. Results are graded from 'A' meaning fully independent to 'E' meaning fully dependent (Appendix B8).

iv. Were expected to remain on the unit for at least 4 months (the duration of the study).

Four participants took part in the study. The participants were identified following the annual DCM evaluation of the unit and the administration of the CAPE to each patient on the unit. The participants are described in brief below.

Participant 1 (P_1), aged 57 years, was diagnosed with Korsakoff's dementia. He had expressive and receptive dysphasia and staff met all his basic care needs. Care staff described him as very restless, and he spent the majority of his day walking around the unit. Care staff also reported that he would grab onto staff members' arms several times a day and he also pulled down his trousers on a regular basis.

Participant 2 (P_2), aged 72 years old, was diagnosed with Alzheimer's disease. He was partially deaf and had expressive dysphasia. He needed assistance in most aspects of his care. Care staff reported that he demonstrated verbal and physical aggression on occasion, the frequency of which increased during physical care.

Participant 3 (P_3), aged 73 years, was diagnosed with Alzheimer's disease. She had expressive dysphasia and therefore her verbal communication was limited. She needed assistance in most aspects of her care. Care staff reported that she exhibited a range of "challenging" behaviours including screaming, putting herself onto the floor and hitting out at staff. Staff were cautious of her as they judged her behaviour as unpredictable.

Participant 4 (P_4), aged 75 years, was diagnosed with Alzheimer's disease. He needed assistance in all aspects of basic care. He was unable to walk and therefore confined to a chair. His communication skills were very limited and he spoke only a few words. Care staff reported he exhibited some verbal and physical aggression on occasions, particularly during personal care.

A summary of the participants' details is provided below in Table 1.[1]

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[1] The details provided are for the final participants who took part in the study.

Participants	Age (years)	Sex	Type of dementia	CAPE score	WIB score
P_1	57	male	Korsakoff's dementia	-9 E (high dependency)	0.9
P_2	72	male	Alzheimer's disease	-7 E (high dependency)	0.9
P_3	73	female	Alzheimer's disease	-7 E (high dependency)	0.2
P_4	75	male	Alzheimer's disease	-9 E (high dependency)	0.9

Table 1 A summary of the details of the participants

Procedure

Once ethical approval was obtained from the Local Research Ethics Committee (Appendix A1) and the participants were recruited, the following procedure was followed.

Development of the revised care plans

An Away Day was carried out with the staff team from the unit in order to feedback the results of the DCM. (Staff were provided with an information sheet about the research, Appendix B9). Ideas were generated about possible changes to the participants' care plans. The care plans were devised with each participant's named nurse. This process utilised the findings from DCM, the recommendations from the staff team and, in some cases, following consultation with the participant's family. The changes to the care plans were as follows:-

Participant 1 The changes made to P_1's care plans are outlined in Table 2 below as an example. These involved increasing his interaction with staff and providing him with occupational activities since he was spending a lot of time on his own engaging in self-stimulatory behaviour. The changes also provided guidance of ways to encourage him to relax periodically, as he was often very restless.

DCM findings
DCM identified that P_1 received very little one-to-one time with staff and he spent large proportions of time on his own doing very little. Interactions with staff tended to occur during personal care, and he was not offered any meaningful occupational activities. The results also identified that his persistent walking appeared to become self-stimulatory and often led to exhaustion.
Aims
1) To increase meaningful interaction and occupation with staff in order to reduce prolonged periods of social isolation, and repetitive stimulation 2) To encourage rest and relaxation.
Plan of action:
▪ Encourage P_1 to spend more time in the communal areas. Greet him and gain his attention. Walk with him, and give verbal and non-verbal cues to increase his visual and tactile awareness of his environment. ▪ Offer him activities and stimulation e.g. listening to music, stress balls, optic lights, walking in the garden. ▪ Provide him with opportunities to rest and relax by: - offering him a relaxing bath in the evening (this is an activity he very much enjoys) - sitting with him, massaging his hands and stroking his head ▪ Respond appropriately to any verbal communication he makes ▪ Be flexible, each interaction may range from a few seconds to a few minutes

Table 2 A summary of the changes made to P_1's care plans

Participant 2 The revised care plans (Appendix B10) provided guidelines to help staff communicate with P_2 more clearly as DCM identified that he often did not appear to understand them, resulting in aggressive episodes. Suggestions were also made regarding occupational activities he may enjoy as he was spending a lot of time on his own.

Participant 3 The changes to P_3's care plans (Appendix B10) involved providing guidelines to increase positive interactions with staff and reduce her social isolation. The changes also aimed to reduce her distress and agitation by helping her to relax more.

Participant 4 P_4 received the standard care available.

	Week 1	Week 3	Week 5	Week 7	Week 9	Week 11	Week 13
P$_1$	Baseline 1 • DCM conducted • Caregiver measures carried out • Standard care received	Baseline 2 • DCM conducted • Caregiver measures carried out • Standard care received REVISED CARE PLAN INTRODUCED	Intervention 1 • DCM conducted • Caregiver measures carried out • Revised care plan continues	Intervention 2 • As week 5	Intervention 3 • As week 5	Intervention 4 • As week 5	Intervention 5 • As week 5
P$_2$	Baseline 1 • DCM conducted • Caregiver measures carried out • Standard care received	Data missing (participant unwell)	Baseline 2 • DCM conducted • Caregiver measures carried out • Standard care received REVISED CARE PLAN INTRODUCED	Intervention 1 • DCM conducted • Caregiver measures carried out • Revised care plan continues	Intervention 2 • As week 7	Intervention 3 • As week 7	Intervention 4 • As week 7
P$_3$	Data collected (void as participant deceased)	Data missing (recruiting replacement participant)	Baseline 1 • DCM conducted • Caregiver measures carried out • Standard care received	Baseline 2 • DCM conducted • Caregiver measures carried out • Standard care received REVISED CARE PLAN INTRODUCED	Intervention 1 • DCM conducted • Caregiver measures carried out • Revised care plan continues	Intervention 2 • As week 9	Intervention 3 • As week 9
P$_4$	Data collected (void as participant deceased)	Data missing (recruiting replacement participant)	Baseline 1 • DCM conducted • Caregiver measures carried out • Standard care received	Baseline 2 • As week 5	Baseline 3 • As week 5	Baseline 4 • As week 5	Baseline 5 • As week 5

Table 3 The data collection and implementation of care plans for each participant

Data collection and implementation of the revised care plans

The timing of the administration of the outcome measures and the implementation of the revised care plans for each participant are presented in Table 3 above. The named nurse for each participant completed the caregiver outcome measures on each occasion to ensure consistency, and the participant's behaviour was rated over the previous two-week period. Four experienced mappers were recruited to carry out DCM. During each observation one mapper was present, and each participant's observation was performed over the same time period to ensure consistency. It was only possible to map each participant for three hours each as opposed to the recommended six hours as a result of limited resources. DCM was performed in accordance with the guidelines described in the DCM manual. Prior to the mapping, inter-rater reliability checks were carried out between the mappers, and a concordance coefficient of at least 0.8 was achieved.

During week 3, three participants became unwell (P_2, P_3 and P_4), and two of these participants died (P_3 and P_4) Two patients who met the inclusion criteria were recruited to replace them in the study. It was not possible, however, to collect data for these participants during week 3, because of limited resources.

The revised care plans were handed over to the staff team shortly prior to their introduction. This was conducted over several handover meetings to ensure all of the staff members were aware of the changes. Additionally, two nursing assistants were assigned to have greater input in conducting the care plans for each participant, to ensure that they were performed consistently. Feedback forms were also devised to be completed at the end of each shift, in order to ensure consistency of the care plans and to monitor progress (Appendix B11).

Results

The results for the caregiver outcome measures, DCM and care staff observations are presented in turn below.

Caregiver outcome measures

Figure 1 shows the caregiver outcome measures scores obtained for each participant over the baseline and intervention phases. The data were normalised to percent (%) score for comparison. Initial visual inspection suggests that some effects occurred. P_1, P_2 and P_3 show an increased score on the quality of life measure (ADRQL) following the introduction of the revised care plans whereas P_4, who received no intervention, remains fairly unchanged. P_1, P_2 and P_3 show a decrease in the agitated behaviour score (CMAI) during the intervention phase whereas P_4 again

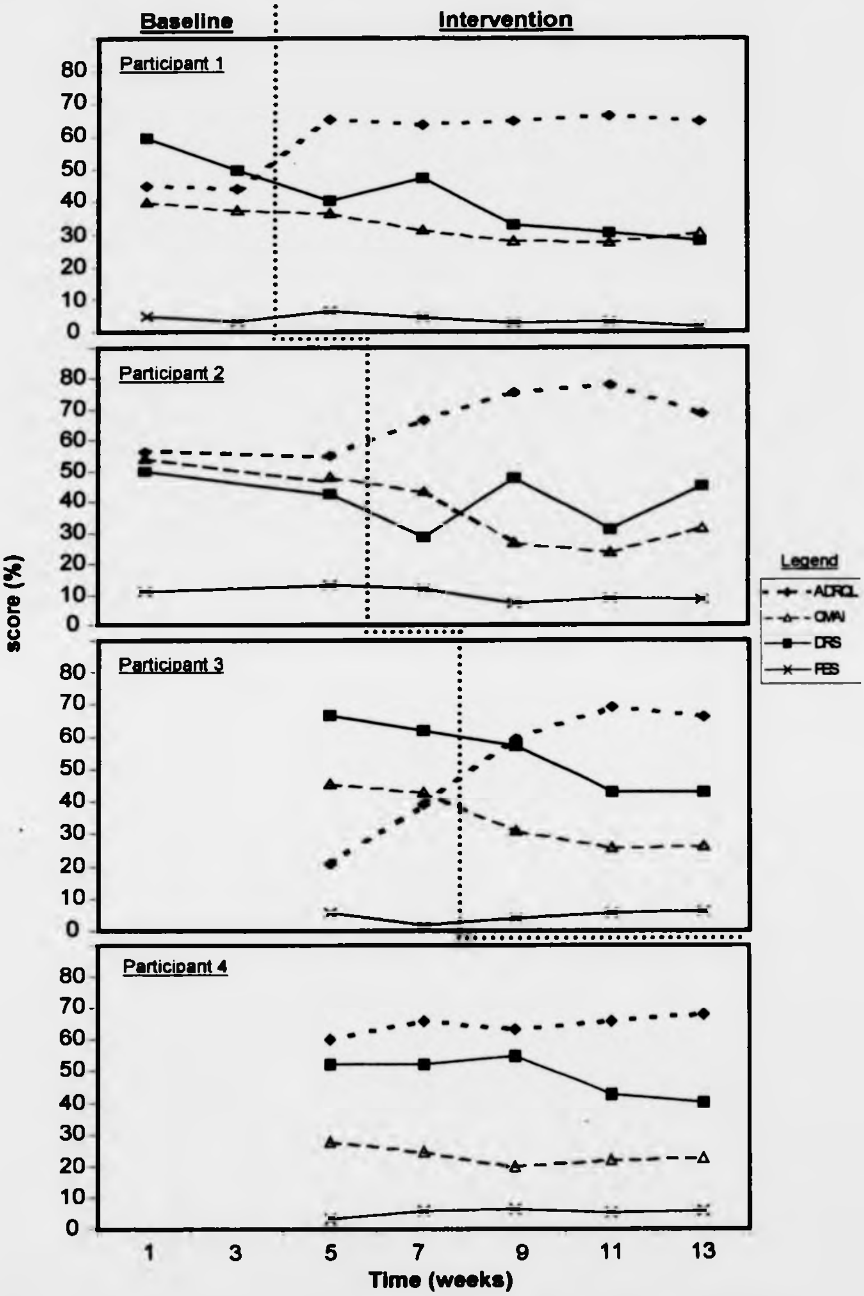

Figure 1 Participants scores (%) for the ADRQL, CMAI, DRS and PES for the baseline and intervention phases

remains relatively constant. A change in the DRS score, however, is less evident, with only P_1 and P_3 demonstrating some reduction in depressive symptoms during intervention. All the participants' PES scores remain relatively unchanged.

To investigate the results further, the data for each participant were visually analysed to attempt to establish whether a change had occurred between the baseline and intervention phases for each measure. Statistical analysis was deemed not to be viable as a result of the limited number of data points, particularly during the baseline phases. In order to qualitatively aid a visual analysis, trend-lines were fitted to the intervention phases and extended to cover the baseline data range. Fitting a linear trend-line to the intervention data assumes linear data; an inspection of the intervention phase data confirms this to be a reasonable assumption for qualitative analysis for the majority of cases. Extending the intervention trend-lines provides a visual comparison of any deviation of the baseline data from the assumed linear trend of the intervention data, hence qualitatively indicating whether a change in trend has occurred between the two phases. This approach offers the advantage (over, for example, a comparison of means) of being less susceptible to errors resulting from any underlying linear trends. It must be stated, however, that even with a qualitative visual analysis, the conclusions that can be drawn from the data are very tentatative as a result of the limited number of data points obtained.

ADRQL

Figure 2 (a) shows the participant ADRQL scores for the baseline and intervention phases. P_1, P_2 and P_3 show an increase in score during the intervention phase compared to the baseline, which is consistent with participant improvement. This increase is illustrated by the positive difference δ between the extended intervention trend-line and the mean of the baseline data points (measured at the

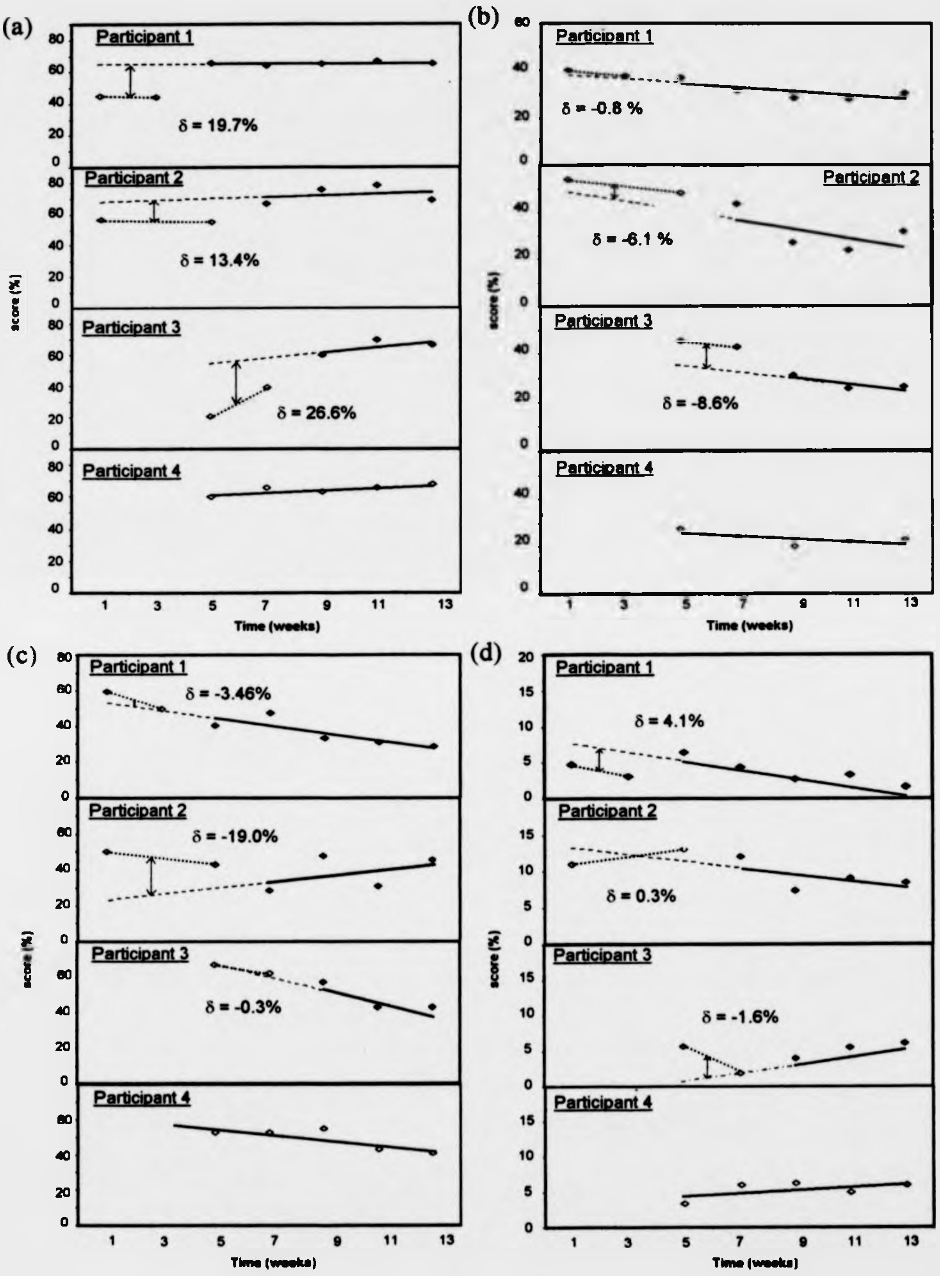

Figure 2 Intervention (solid) and extended intervention (dashed) trend-lines, with the extrapolated difference δ at baseline mid-point, for each participant for the a) ADRQL, b) CMAI, c) DRS and d) PES measures. (Key: baseline ◊, intervention ♦)

baseline mid-point), the increase ranging from approximately 13% to 27%. The trend-line of P_4, who had no intervention, is relatively linear with no obvious discontinuities. This is consistent with the increase in P_1-P_3 arising from the intervention. The origin of the slight positive slope of P_4's trend-line (an increase of 1.6% per fortnight) could be a carryover effect, but this rate of increase is minor in comparison to the observed increases between phases for P_1-P_3.

CMAI

The participants' CMAI scores are presented in Figure 2(b). P_1 shows no change between the two phases, as substantiated by the small difference between the baseline mean and the extended intervention trend-line (δ = -0.8%). P_2 visually shows little change. In this case, the intervention trend-line is a poor a fit to the data (which shows high deviation from the linear trend) and hence this extended trend-line measurement should be ignored. P_3 shows a decrease at intervention (δ=-8.6%); this is consistent with the expected lowering in the score for this measure with participant improvement. The trend-line for P_4 is relatively flat with no discontinuities. Again, a slight negative slope is observed (a decrease of 1.2% per fortnight), which is indicative of there being a degree of carryover.

DRS

Figure 2 (c) shows the participants' scores for the DRS. Visually there is no change for P_1 and P_3 between phases. This is confirmed by the small difference between the baseline means and the extended intervention trend-lines (δ= -3.46% and –0.3% respectively). P_2 also shows little change on visual inspection. The intervention trend-line is a poor fit to the data and hence no conclusions should be drawn from the δ value. The trend-line for P_4 is moderately flat and continuous, and the slight negative slope is indicative of a small carryover effect.

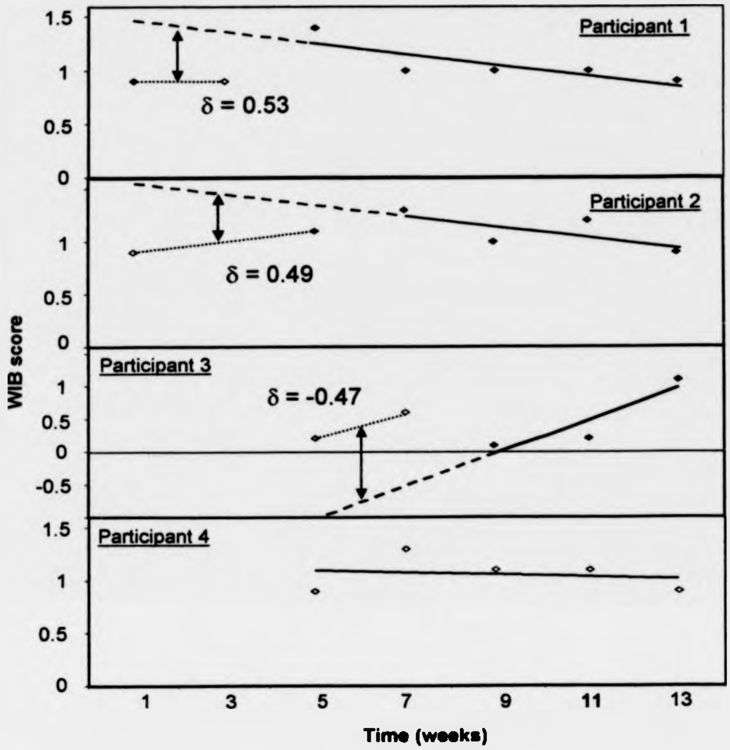

Figure 3 Intervention (solid) and extended intervention (dashed) trend-lines, with extrapolated difference δ at the baseline mid-point, for each participant's WIB scores (Key: baseline: ◊, intervention: ♦)

PES

Figure 2(d) shows the participants' PES scores. P_1 show an increase between phases (δ = 4.1%), consistent with the positive outcome anticipated from the intervention. For P_2 and P_3, no change is apparent. The data for P_4 is relatively even, and the slight positive gradient (0.4%) is consistent with a small degree of carryover.

DCM

Individual WIB scores

Figure 3 shows the participants' aggregated WIB scores for the DCM observations. The data were visually analysed using the procedure described as above. P_1 shows an initial increase in WIB score (δ = 0.53), consistent with an increase in well-being. However, this increase is not sustained over the duration of intervention. P_2 and P_3 show no visual change, with poor fitting of intervention trend-lines; hence no conclusions are drawn for these participants. P_4 shows no sharp discontinuities, with a negative slope indicative of a small rate of decrease in well-being.

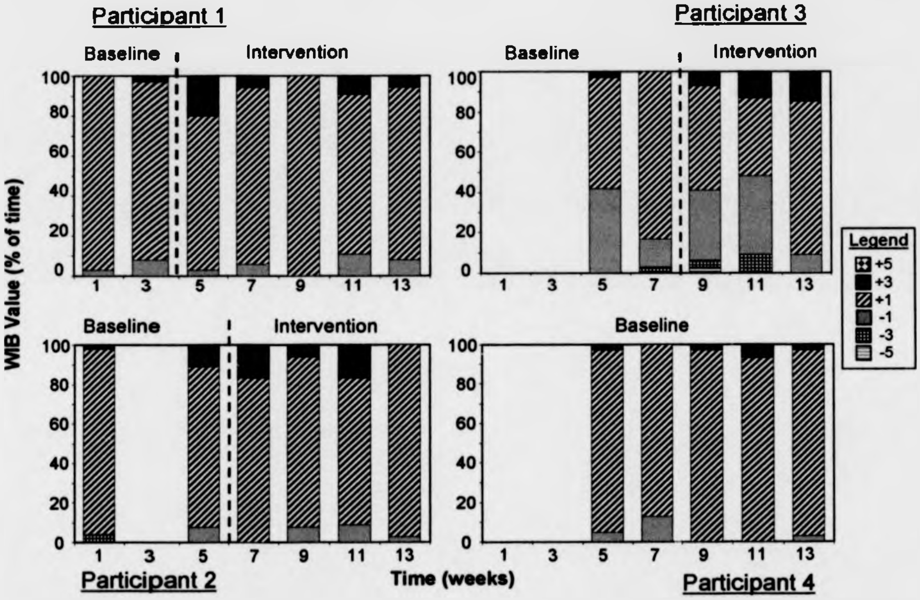

Figure 4 Percentage of time (%) spent in each proportion of the well-being scale for each participant

WIB value profiles

The WIB value profile represents the amount of time the participants spent in a state of well- or ill-being, as scored on a scale where a negative value indicates 'ill-being' and a positive value indicates 'well-being' (ranging from –5 to +5 in increments of 2). Figure 4 shows the percentage of time the participants spent in each band of the well-being scale. From visual inspection of the data, no remarkable effects can be seen for any of the participants, indicating little change in well-being between the baseline and intervention phases. The anticipated results were that each participant would spend a larger proportion of time within the positive values of the scale during the intervention phase.

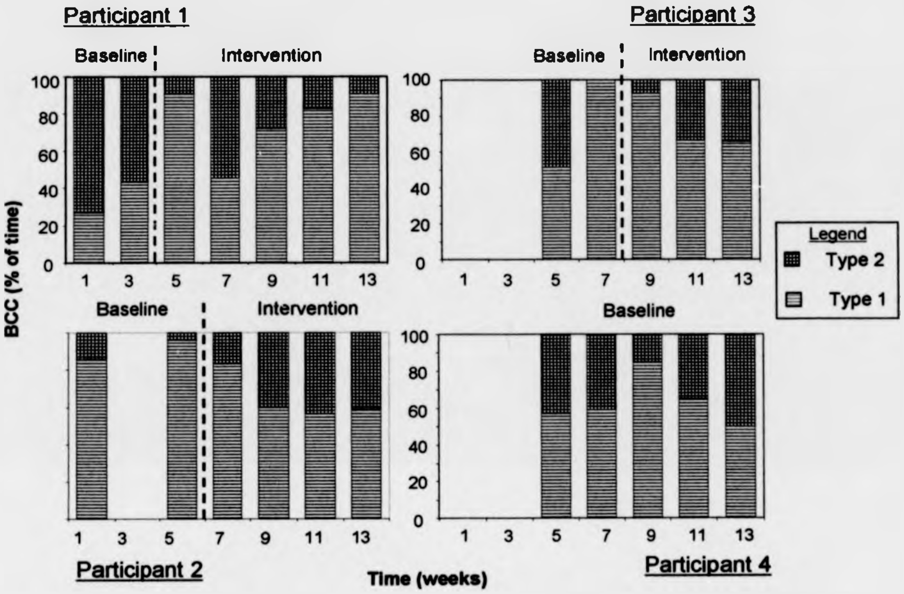

Figure 5 Percentage of time (%) engaged in Type 1 (*A E F G H I J L M O P R S T X*) and Type 2 (*B C D U W Y*) behaviours for each participant for the baseline and intervention phases

Behaviour category codes

The behaviour category codes indicate how each participant spent their time during the DCM observations. They were analysed by dividing the 24 codes into two behaviour type categories. Type 1 behaviours have the potential for well-being (*A E F G H I J L M O P R S T*) whereas Type 2 behaviour often indicate ill-being (*B C D U W Y*). The behaviours were categorised according to the DCM manual (Bradford Dementia Group, 1997)[2]. It is noteworthy that engaging in Type 1 behaviour does not necessarily equate to an increase in the individual's well-being. Figure 5 shows the percentage of time each participant was observed engaged in

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[2] The behaviour codes for walking (K) and sleeping (N) were not included, as they are not incorporated into these categories

Type 1 and Type 2 behaviours. For P_1 an increase in Type 1 behaviours is observed during the intervention, which is indicative of there being a greater potential for well-being. However, the opposite is observed for P_2. No obvious change can be observed for P_3. P_4 demonstrates an increase in Type 1 behaviours at week 9, which is consistent with a small carryover effect, although this is not maintained.

Care staff observations

Staff members verbally reported observing positive changes in some of the participants. They also reported a change in their behaviour towards the participants. Unfortunately, the feedback forms intended to document the staff members' observations of the participants' progress were completed too infrequently to draw any firm conclusions.

The verbal reports from staff members for each participant are summarised below:

Participant 1 The positive changes observed in P_1 were that he demonstrated more eye contact and smiled and laughed more. Care staff also noted that P_1 was pulling his trousers down less often. Many staff reported that they were attempting to interact more with P_1. This was confirmed by the observations of one of the mappers.

Participant 2 Staff reported that initially P_2 seemed to benefit from the intervention, and that staff members were interacting with him more frequently. However he became physically unwell during week 9. He became difficult to engage, more withdrawn and less physically aggressive. This may offer some explanation for the reduction in his aggression and increase in depression on the measures at this time. Staff also reported that they tended to interact with him less often.

Participant 3 Staff reported that P_3 became more relaxed, and her levels of distress were reduced. Staff said that they were interacting with her more positively, and that she was spending more time in the communal areas. They reported feeling a lot more confident interacting with her and were more proactive when they judged she might become distressed. Further, they were trying out more activities; in particular she enjoyed sensory activities (e.g. hand massages).

Participant 4 Staff reported that they felt they had not changed their approach toward P_4 and they reported little change in his behaviour.

Discussion

The results from the caregiver outcome measures are suggestive of some positive changes. P_1, P_2 and P_3 demonstrated an increase on the quality of life measure, whereas P_3 showed a decrease in agitated behaviour (a component of well-being). Staff also verbally reported observing positive changes in the participants. However, although these results lend some support to the initial hypothesis that the use of DCM to inform care plans would result in an increase in well-being and quality of life, conclusions about the effects of the revised care plans and therefore the use of DCM as a care planning tool should be drawn with caution from this study. The results from DCM suggest little conclusive improvement in well-being for the participants following the introduction of the revised care plans. Further, the validity of all the data is limited as a result of the insufficient data points that were collected. In particular, the two-point baselines acquired were inadequate for meaningful comparison with the intervention data. Consequently, it was not feasible to conduct statistical analysis to determine whether the differences between the baseline phase and introduction of the revised care plans were significant. It could also be argued that DCM did not have an effect on the well-being of the participants but only impacted on staff, as was indicated by staff reporting a change in their behaviour. Therefore, the results of this study do not provide support for DCM as an effective tool to inform individual care plans for people with dementia in long-term care.

Limitations of this study

There were several difficulties in conducting this study, which may have affected the conclusions that can be drawn from the results. Each of these will be discussed below.

The outcome measures used

There are a limited number of appropriate outcome measures for people with dementia (Bond, 1999), and hence those chosen for this study may not be ideally suited. Further, the measures selected may not have the sensitivity to detect the subtle changes associated with improvement in well-being in people with severe dementia (e.g. eye contact, smiles and gestures; Perrin, 1997). For example, DCM measures well-being through engagement in behavioural tasks. Spaull, Leach and Frampton (1998) also experienced difficulties when using DCM as an outcome measure, finding it did not detect any impact for a multi-sensory intervention they used with people with dementia. Similarly, the ADRQL scale was not sensitive to the more subtle changes in the participants' behaviour reported by staff. For example, it would measure whether behaviour occurred rather than its frequency of occurrence. Further, the use of the alternative CMAI measure that incorporates an intensity rating as well as frequency (Cohen-Mansfield, 1999) may have improved the scope of the outcome data. The PES was also not ideally suited for use with people with more severe dementia since the activities they are more likely to engage in are not listed on the scale (e.g. multi-sensory occupations such as massage; Perrin, 1995). The majority of the outcome measures employed in this study relied on reports from care staff. The use of such measures has been criticised for people with advanced dementia, as important information may be lost in comparison with direct observation of these individuals (Volicier et al, 1999). In addition, the reliability of the caregiver outcome measures may have been affected, as the care staff that completed the measures were not blind to the participant's stage of intervention.

Issues relating to the participants

Conducting research with this group can be fraught with difficulties, as experienced during this study. For example, one of the participants was unwell throughout the study. This resulted in data collection difficulties. His illness may also have affected the reliability of the data collected. In addition, two participants died during the study, and, although replacement participants were recruited, this resulted in considerable disruption to the data collection process. This highlights the difficulties inherent in conducting research with vulnerable individuals. The rapidly changing needs of this group of individuals also posed a problem. For example, P_2 became unwell and as a result his care plan became unsuitable. The reduction of time staff spent with P_2 as he became more dependent also highlighted the "inverse care law" (Bruce, 2002), which states that the most dependent patients receive the least staff interactions. Additionally, dementia is a progressive condition and therefore changes may have occurred in the participants anyway.

Organisational issues

DCM requires organisational support in order to conduct the observations and to also carry out the recommended changes to care delivery (Brooker, 2002). Difficulties were experienced in relation to both these areas during this study. It was problematic to recruit staff to carry out the mapping. This placed limitations on the amount of data that could be obtained, and also on the reliability of the data since ordinarily two observers would be present as opposed to the single observer used in this study. This resource limitation also resulted in observation periods being reduced to half the recommended minimum time period. Additionally, the author had to conduct some of the DCM observations; this inevitably may have introduced a bias into the study since she was aware of the participants with changed care plans.

There was a large amount of staff sickness over the period of this study, which is a common problem in this type of unit (Keough & Huebner, 2000). This resulted in an insufficient number of staff being on duty to carry out the individualised care required, and the presence of agency staff that were less familiar with the participants and the revised care plans. Further, despite training, some staff held negative attitudes toward person-centred care and were less motivated to carry out the care plans. All these factors may have affected the consistency of the care plans.

To summarise, there are many problems inherent in conducting research with people with severe dementia in long-term care. These include difficulties assessing quality of life and well-being in a group with limited communication. Also, problems of ill-health and death make it difficult to guarantee participant involvement. Further, DCM is resource intensive, and organisations need to be willing to not only support the process of mapping, but also to allocate sufficient resources for implementing the DCM recommendations i.e. supporting person-centred care.

Recommendations for future research

The findings of this study do not support the use of DCM as a care-planning tool. However, the practical limitations of the study have made it difficult to draw any firm conclusions. The inconclusive nature of the results indicates that further investigation into this area may be worthwhile. This study has served to illustrate some of the difficulties inherent in this type of research, and the following recommendations can be made for future work:-

1. It is imperative to conduct such a study over a longer period of time, and possibly with increased observational frequency, to ensure the collection of sufficient data points for both baseline and intervention phases.

2. To recruit a greater number of participants, particularly in view of fact this is a very vulnerable group and illness or death can occur.

3. It would be of benefit for the participants to be within different care environments to avoid potential carryover effects.

4. To select measures more sensitive to change in people with severe dementia. The Positive Response Schedule (Perrin, 1997) has demonstrated usefulness in this area (e.g. Hadley, Brown & Smith, 1999).

5. To conduct the research with organisational support to aid the DCM evaluation process and the introduction of changes to care delivery.

6. To investigate the use of shorter, less time consuming methods to inform care-planning. This study illustrated that clients' needs can change very rapidly, hence care plans may need to be revised regularly and DCM may be too labour intensive for this purpose.

7. In view of the high amount of staff sickness and turnover in long-term care settings, investigations into how to implement care plans in the reality of a rapidly changing staff group may be of use.

Conclusion

DCM is the current tool of choice for informing person-centred care for people with dementia, and it is widely used within health and social care settings. A lot of time and resources are involved in the setting up of a DCM evaluation and carrying out the changes to care practice. Therefore, research to investigate its effectiveness is of great importance. This research has provided a first step towards examining the use of DCM as a tool for informing care plans. The research has been unable to draw conclusive results about the usefulness of DCM in this way. However, it has highlighted issues for future research and potential ways forward.

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Chapter 3

Care staff's experience of Dementia Care Mapping

Abstract

Dementia Care Mapping (DCM) is widely used within the NHS to evaluate and inform the care provided to people with dementia. Yet it remains unclear whether care staff actually find it useful to improve their care practice. This article describes a study in which interviews were conducted with care staff working within an NHS formal care setting that had been evaluated using DCM. The purpose of this study was to explore staffs' experience of the DCM process, their perception of its usefulness and the potential difficulties experienced in implementing changes to their care practice. The results are analysed using thematic analysis and indicate that, overall, DCM helps staff to become more reflective in their care practice and increases their job satisfaction. The results also suggest that DCM might benefit by ensuring that staff are more involved in the process.

Introduction

Dementia Care Mapping (Kitwood & Bredin, 1992; Bradford Dementia Group, 1997) is an observational tool used widely within health and social care settings to evaluate and implement person-centred care (Parker, 2001). Person-centred care is conducted within the context of a supportive relationship and involves valuing the person with dementia. It also means providing individualised care to help dementia sufferers live as fulfilling a life as possible, focusing on their remaining abilities rather than their deficits (Kitwood, 1995; Morton, 2000). Dementia Care Mapping (or DCM) is potentially a stressful experience for care staff since it involves conducting detailed observations within the care environment. Additionally, DCM entails providing feedback about care staff's direct care practice. This includes episodes where it is judged that the carers have depersonalised the person with dementia. These episodes are termed "malignant social psychology"; an example of this is "infantilisation", where the person with dementia is treated in a patronising manner (Kitwood, 1997). The individuals that conduct the observations (or mappers) are trained to provide the DCM feedback in a sensitive and constructive manner. However, care staff may view this experience as a criticism of their practice (Bolton, Gee, Jackson et al, 2000). Further, DCM involves modifying care practice and therefore relies on staff accepting the feedback and adopting a person-centred approach. Despite this, there is a paucity of research into care staff's experience of DCM, and some evidence suggests that person-centred care is difficult to implement in practice and is not commonplace.

Care staff's experiences of DCM

The few studies that have investigated care staff's views of DCM have reported a positive response. For example, Brooker, Foster, Banner et al (1998), using a staff acceptability questionnaire, found that the majority of staff in formal care settings thought DCM was useful in improving care., Similarly, Barnett (1995), in her use of DCM found that most staff reported it was a positive growth experience. However, the investigation into staff members' views was a secondary consideration in both of these studies. Packer (1996) focused solely on the experiences of care staff that had undergone training in the DCM method. Although it was judged that DCM had a positive effect on care practice, this is a descriptive article based on the accounts of three care staff that were likely to have a more positive view of DCM as they had chosen to be trained in the method. Further, Bolton et al (2000) experienced the opposite when introducing DCM to an NHS Trust, with staff experiencing difficulties in accepting the DCM feedback.

Person-centred care in practice

Research suggests that the care provided in formal care settings continues to focus primarily on the physical and not the psychosocial needs of the patients (e.g. Innes & Surr, 2001). Such care is not truly person-centred, and there are many potential barriers to its implementation. People with dementia have complex needs (Marshall, 2001), and are a challenging group to care for (Brooker, 2000). Care is often provided within organisations that offer inadequate training and support to staff (Marshall, 2001). Further, the staffing levels are not sufficient to support individualised services (Keating, Fast, Dosman & Eales, 2001). These factors may result in staff possessing "neither the energy nor motivation to provide little more than physical care" (Marshall 2001, p 410).

Rationale for this study

Relatively few research studies have investigated staff views of DCM, and they are mainly descriptive accounts yielding inconclusive results about the experience of DCM. Further, although there is some suggestion that DCM is useful in improving care, there is no information about the useful aspects and the practicalities of implementing person-centred care, which seems to be difficult to conduct in practice. This is particularly important since DCM is the tool of choice for evaluating and informing care practice within the NHS (Audit Commission, 2000).

This study explores the experience of a staff group that had undergone the DCM process. More specifically, the research investigates the DCM evaluation experience, what care staff found useful about the method, and potential practical difficulties encountered. A qualitative approach was judged most suited to the exploratory nature of this research. Therefore, a small number of formal care staff, identified as having a range of views about DCM, were interviewed.

Method

Participants

Four care staff took part in the study (one male, three females). They were of mixed qualifications (one qualified nurse, three nursing assistants) and were recruited from an NHS Trust that had introduced DCM to the care services for older adults with dementia. The length of time they had worked with people with dementia ranged from 2 to 25 years (9 years on average). They had all received some training in person-centred care, though none had been trained in the DCM method. All of the participants were based in a continuing care ward for people with dementia that had recently undergone the annual DCM evaluation. The results of DCM had been fed back to staff, and changes to care delivery were underway.

The researcher

At the time of the study, the researcher was a psychologist in the final year of clinical psychology training. She had a number of years experience of working with people with dementia as a care assistant. She was trained in the method of DCM and held the belief that this method could be effective in improving the care provided to people with dementia.

Procedure

Selection of participants

The participants were selected following the administration of a screening questionnaire (Appendix C1). This questionnaire was issued to all of the staff team on the ward (sixteen in total) and aimed to determine staffs' general views of DCM. The participants represented the two members of staff who were judged to view

DCM the most positively, and the two that viewed it least positively. Informed consent was obtained from the participants to ensure that they were willing to take part in the study (Appendix C2).

Interview guide and procedure

A semi-structured interview format was developed and aimed to explore staffs' views about DCM based on the following areas: the experience of being mapped, the aspects of DCM they found useful, and practical considerations (Appendix C3). Each interview was recorded and lasted between 30-45 minutes.

Data analysis procedure

The interviews were transcribed and subjected to thematic analysis to identify the main themes, using open and focused coding (Charmaz, 1995). The method of open coding involves examining the transcripts in detail and applying a series of codes that describes the content. The codes are then organised into a number of conceptual categories which best captured the data, a process referred to as focused coding.

Methods used to ensure validity

The credibility of the codes and categories were checked using methods described by several authors (e.g. Elliott, Fischer & Rennie, 1999). Firstly, an audit trail was created illustrating the open coding of the data (Appendix C4), and outlining the way in which the codes were organised into categories (Appendix C5). Secondly, a colleague with substantial experience of this research method reviewed the coding of the data. Finally, the participants were asked whether the analysis fitted with their experience (all of them agreed that this was the case).

Results

The analysis identified five themes that provide insight into care staff's experience of DCM and the impact it has had on them. These were as follows:

- Care staff's development and changes in care practice
- Care staff's feeling in relation to their role
- Limitations of the DCM method
- The context in which DCM is conducted
- Care staff's views of their patients with dementia

Each is discussed in turn.

Care staff's development and changes in care practice

DCM appeared to encourage staff to be more reflective about their practice, showing more awareness of the ways in which they interacted with patients. This was demonstrated by their consciousness of episodes of "malignant social psychology" (Kitwood, 1997), such as "ignoring" (that is carrying on a conversation as if the person was not there). For example, one staff member is quoted as saying,

> I feel guilty talking in front of patients and if I find myself doing it I slap myself on the wrist, I shouldn't do it.

DCM also helped staff to develop a greater understanding of their patient's behaviour. For example,

> Another patient…who paces…walks and walks. We thought he was quite happy doing that, and it was pointed out…no…that wasn't the case.

The increase in care staff's awareness of their care practice impacted on their care provision; they interacted more with the patients, treated the patients as individuals and tried out more activities with them.

Care staff's feeling in relation to their role

DCM helped staff feel better about their role and this was demonstrated in several ways. Some care staff described feeling more empowered and confident in the work that they did with patients. For example,

> I used to be so quiet and laid back and I used to think, well I'll wait until somebody says.... but now I just sort of want to do more.

Staff also reported that they gained enjoyment from the different activities they were doing with patients, and the positive responses they received were a reinforcing experience. DCM also provided staff with motivation to make changes to their practice, and they felt it enabled them to spend more time with clients. However, they also said that they wanted more support and recognition for the role that they perform.

Limitations of the DCM method

The limitations of the method were mainly related to the impact the process had on staff members' feelings. Some staff members' felt judged during the observations and this was evident in their concern about making mistakes, and feeling it was necessary to try to perform better. However, for others it was a less threatening experience and they were able to carry on as normal. DCM also appeared to make some staff feel disregarded, as they did not feel they had the opportunity to share the knowledge they had about patients with the mappers. For example,

> We have a lot of dealings with these patients and we should be more involved with the mappers.

Care staff also reported that the well-being of the patients could be misunderstood because they perceived that the mappers lacked knowledge about the patients. The large degree of variability in the patients' presentation and the lack of time spent carrying out the observations were also judged by staff members as areas where misinterpretations could arise. For example,

> They missed out on all the good bits that we were doing and only saw the negatives so it is not very rounded in that respect.

The misunderstanding of the patients was also reflected in staff members' disagreement with some of the activities suggested during the DCM feedback. Further, some staff did not feel able to voice their opinions, and one staff member described how she felt unable to put her point across, during the feedback session. Staff also said they would have liked more information from the mappers prior to the feedback to give them the opportunity to prepare.

The context in which DCM is conducted

There were many restrictions to implementing changes in care practice, including the difficulties of working with staff that lacked belief in providing person-centred care. One participant gave her hypothesis about the reasons for this:

> I don't know what the answer is but some staff have been doing this for too long and they are just tired and burnt out.

The low staffing levels and high number of agency staff also made it difficult to individualise care, and this was worsened by the high physical needs of patients and restrictions of the environment (e.g. lack of space). However, despite these difficulties, DCM had some impact on the care environment with care staff feeling it was happier and more relaxing for patients. For example,

> DCM encourages more of a homely feeling and having people who are caring towards the patients. It helps them, it relaxes them and they feel safe with us.

Care staff's views of their patients with dementia

The final theme that emerged provides some insight into how these care staff viewed their patients. They considered their patients needs as being of great importance. For example,

> I will go and do something else, but I can do that anytime, it is the residents who need the care not the building.

There was a sense that they felt people with dementia were a neglected and misunderstood group within the health system. They also demonstrated awareness that people with dementia have the same needs as anyone else. For example,

> It could be all physical care just because it's older adults. That is important but then so are their emotional needs.

DCM provided care staff with new insights into the abilities of their patients, as this method encourages staff to give patients independence in daily activities. For example,

> It's easier to do things for them... but, giving them that opportunity to do more for themselves, it's quite surprising how much they can do.

Further, they considered their patients to be very changeable from day to day, requiring flexibility in care practice. They also communicated experiences of their patients deteriorating, which seemed to make working with these patients more difficult.

Discussion

The results of this study are encouraging in that care staff report that DCM has a positive influence on care practice. Care staff also said that the DCM feedback is useful as it provides them with a different perspective of their work and their patients, and it gives them new ideas to inform their practice. DCM also plays a part in helping them feel more worthwhile in their role, which provides some support for one of the claims of the DCM method (Brooker, 2002).

However, in accordance with the findings of Bolton et al (2000), this study highlighted that the process of DCM can be an uncomfortable experience for staff; in this case making them feel judged and intimidated. It also emerged that staff often felt excluded from the DCM process. They viewed the mappers as seeing themselves as the experts, with the knowledge that staff had about the patients not being taken into account. The DCM feedback aims to be a collaborative process, but this was not apparent from the accounts of these staff as they felt unable to put their point across. The concerns raised by staff that the DCM observations may be a misrepresentation of the care delivery have also been shared by others (e.g. Edwards & Fox, 2001).

Although the negative attitudes of some care staff provided an explanation for the difficulties in implementing person-centred care, this staff group appeared particularly aware of the needs of their patients. In the main, the limitations were because of a lack of resources, as highlighted by Keating et al (2001) and Marshall (2001).

Conclusions and Recommendations

Improving the quality of care for people with dementia has become increasingly more important as indicated by recent reports (e.g. Audit Commission, 2000). DCM is potentially a very useful tool for helping staff improve and develop their care practice. This study has demonstrated the importance of providing DCM feedback in a collaborative and constructive manner, and suggests that the staff members in this role may need more guidance and training. McKenzie, James and Lee (2002) have begun this process by providing some practical guidelines. This study also indicates that it may be useful to explore ways to include staff and incorporate their knowledge about their patients into the process; for example, socialising staff to the method, asking their opinions, and providing a debriefing session at the end of the observation to clear up any potential misunderstandings. However, it is questionable whether this would be practical since DCM already takes a great deal of resources. It may also be beneficial to develop ways to help staff work within the restricted resources that are commonplace in care settings for older people with dementia.

This study is limited as the findings are based on the experience of a small number of staff in one care setting. It is therefore by no means a full representation of the care staff's experience of DCM, and conclusions should be drawn from the results with caution. Additionally, further data collection and analysis using a grounded theory approach would have provided further elaboration and support for the themes identified. However, the themes raised in this study do suggest that further investigations may be warranted, involving an increased number of staff from different care settings to see if these themes are replicated. As Jacques and Innes (1998) have argued, in order for person-centred care to take place it is important to explore the viewpoint of those who care for people with dementia.

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Chapter 4

My Research Journey

Introduction

My research journey has been an incredibly challenging experience. In this review, I shall reflect on some of the reasons I chose to conduct research within the area of improving care for people with dementia in long-term care. I will also consider some of the difficulties I encountered whilst conducting the research, and the personal impact on myself. I shall conclude by reflecting on where my beliefs now lie with regards to providing care for people with dementia. My personal learning and some of the implications for clinical psychology training are also discussed.

The beginning of my journey

My experience of dementia care

I have had a variety of clinical experience working with people with dementia in long-term care, and during this time I have become bothered by the poor quality care these individuals often receive. This includes poorly resourced care environments, little acknowledgement from care staff of their psychological and social needs, being treated with a lack of respect and dignity and thus spending most of their time sitting in a chair not doing very much. Many others have shared my observations; for example, Bowie and Mountain (1993) noted that in dementia care settings "two thirds of the day is spent doing nothing"(p857). A number of authors have also shared my dissatisfaction with the care systems (e.g. Brooker, 2000).

In my experience, working with people with dementia can be incredibly rewarding and enjoyable. These individuals are going through a very frightening experience, and other client groups who face emotional distress usually get offered some form of support whilst people with dementia invariably don't (Bender & Cheston, 1997). Further, there is a likelihood that somebody we know, or even ourselves, will develop dementia, and, as there is no cure, it is in our interest to invest in care for such individuals. As Scott (2001) stated concisely "one day it may be us sitting in that chair with no way of communicating our distress" (p1427). Yet there is a lack of research into improving care for people with dementia.

During my clinical work, I have found it very difficult to affect change within formal care settings for these individuals. I have often been faced with deeply entrenched negative attitudes and beliefs about the nature of dementia and dementia care i.e. " the old culture of care" (Kitwood & Benson, 1995). This has often left me feeling frustrated, exhausted and hopeless, as if "I was fighting a losing battle". Yet I held the belief that more could be done for these individuals, and experiences during my clinical work provided me with encouragement. For example, successfully comforting a frightened woman with dementia who didn't know where she was and receiving applause from a client during a group activity "for being bothered" with them. I have also encountered some incredibly positive and enthusiastic staff.

Making a difference to dementia care

An introduction to Tom Kitwood's ideas of person-centred care and training in the Dementia Care Mapping method (DCM) gave me some hope (Kitwood, 1997). His ideas fitted with my experience and philosophy about how care could be provided; essentially, trying to understand the individual's experience, providing them with care to support their individual needs and treating them like human beings with the respect and value they deserve. Hence, I became interested in whether

DCM could actually work in practice and make a difference to the care settings I had worked in, and from here the idea of conducting research into this area developed.

I considered different ways I could conduct research with DCM e.g. making improvements to the DCM method (such as developing a positive care rating scale) or developing it as a briefer method. I settled finally on the idea of informing care plans, as this seemed of importance since DCM is increasingly being used to inform care yet it lacks empirical support. Further, from discussion with colleagues this seemed a very clinically relevant project and it seemed manageable within the time-scale and resources available. I was also very interested in care staff views about DCM as, in my experience, the observations could be hugely anxiety provoking and the recommendations to care provision could be viewed as a criticism.

A bumpy road

I approached this research project with some trepidation and anxiety. I knew it wasn't going to be easy, given the system I was going to be working in, but I held the belief that DCM could make a difference. I had also not conducted research since my days as an undergraduate, and therefore I felt very unsure of my skills as a researcher. As it turned out, the main challenges were the practical difficulties I encountered during the research.

Recruitment issues

One of the first difficulties I came across was finding a location to conduct the research that could support DCM and provide the participants for the amount of time necessary (i.e. continuing care patients). I found one location and gained ethics approval only for the ward policy to change, which meant it was no longer providing continuing care and therefore could not guarantee the participants. I spent weeks telephoning and visiting many wards and nursing homes but although most were interested in the project, they could not meet both these criteria. I had intended to conduct the research within two locations, however I had to settle for one ward, which was not ideal. Further, although the NHS Trust where the ward was based had introduced DCM to all of its care settings, the ward was poorly resourced and the manager would only agree to the involvement of four participants (I originally planned for six). Further, data collection was delayed, as I had to fit into the schedule of the Trust's yearly DCM evaluation project.

I had little back up if anything happened to the participants. My worst fears were realised when three participants became unwell and two of these died during the study. This impacted on the research, as it was necessary to recruit more participants and repeat a lot of the work that had already been carried out (e.g. planning changes to care provision). It also meant that I didn't have as much data as I anticipated which compromised the conclusions that could be drawn from the study. I also disliked how the stress of completing the research impacted on my feelings about the death of the participants; I was more concerned about obtaining replacements than feeling saddened by their deaths.

Working with the staff team

One of the biggest challenges of the research was trying to work effectively with the staff team. It took a great deal of organisation to plan and feedback the changes to the care provision. Even with all this effort, poor communication between the team meant that some staff were unaware of the changes, which was extremely frustrating. A number of staff were resistant to my involvement and "couldn't see the point", therefore they were less keen to carry out the care plan changes. Further, it was exasperating arriving on the ward to find a number of agency staff and to realise that the care plans were not being done. However, a lot of the care staff were very interested and positive, and they enjoyed trying to work differently with clients. Unfortunately, this has not continued since I withdrew from the unit. This suggests to me that staff will try to provide for their clients' psychosocial needs if they have some support, and if this is given priority.

Finding trained mappers to give up their time to conduct the observations was a challenge even though there were many trained mappers within the NHS Trust. This resulted in having to conduct a large proportion of the mapping myself, which was very time-consuming. However, I was also heartened by the busy clinicians who felt strongly enough to give up their time and support the research, which I know was not easy for them.

The interviews I conducted with staff were an enjoyable part of the research and humbling at times. It is easy to be critical of care staff's performance, as I often found myself being. However, the staff I interviewed came across as very caring individuals who felt they were doing the best for their patients, but were frustrated with the lack of resources they found themselves working with.

Personal impact

I was very reliant on others during the research (e.g. staff and the mappers), and often felt a lack of control, extremely anxious and a great deal of frustration. I have since realised that some of the feelings I was experiencing parallel those described in the literature by people with dementia (e.g. Bender & Cheston, 1997) and I feel this may have provided a small degree of insight into how terrible their experience must be.

Whilst I was carrying out the DCM observations I often felt perturbed by the restriction of my role, as I wanted to interact with the patients around me. I also felt uncomfortable pretending I was not present, and thus ignoring the interactions made by the patients. It was difficult to witness poor care practices such as staff talking about patients as if they were not there, treating patients with disrespect and the lack of privacy afforded to patients. Neel (2002) talked about the powerful emotions that can be raised during mapping when witnessing poor care, and I often found that I felt angry and helpless. However, over the course of the observations, I also found myself making excuses for staff and denying the occurrence of poor care practices. I think this was a way to protect myself from what I was seeing. If my relatively short time on the ward had this effect on me, I wondered what impact it must have on staff. It is likely the depersonalisation of patients that I witnessed was a way of helping them cope. I also found it difficult to observe people who had immense disabilities and were at the end of their lives. Some of my feelings were similar to those described by Ramsey (1995) during her observations on palliative care ward and included feeling very sad, hopeless and helpless.

Ethical considerations

During the observations, I was faced with care practices that were not just poor but, I felt, were neglectful of the patient's needs. For example, one patient (who was not involved in the study) was isolated in a room by himself, with no stimulation, for long periods of time because of his aggressive behaviour. He often presented as very distressed during this time. I felt extremely uncomfortable witnessing this situation and as a clinician I felt this could be managed better. However, as a researcher I had no authority to intervene. I also had concerns that my interference could damage the rapport I had with staff, who were not acting out of cruelty but desperation. I gently enquired whether staff had considered other options but I was told that they felt this was the best way to proceed. I felt unsure how to deal with this dilemma, but, after some consideration and discussion with my research supervisor, I decided to discuss the situation with the clinical nurse specialist within the Trust, who had some responsibility over the ward and whom I trusted to deal with the situation sensitively. To my relief the situation improved and staff seemed to welcome the support they received.

Another ethical concern that arose was conducting research without obtaining consent from the participants. This raised the question whether we have the right to include participants without their consent. This was something I felt uncomfortable about but overcame by ensuring ethical principles were adhered to during the research. The participants did not come to any harm and if they had become distressed or showed a continued lack of interest in relation to the changes to their care, they would have been withdrawn. Further, their privacy was respected in that they were only observed in public areas and their confidentiality was maintained, as they are not recognisable from the research. The research was also carried out in their best interests.

Expeditions are necessary

The usefulness of DCM

At the end of my journey I feel disappointed and disillusioned that I was unable to affect any significant changes to the care provided to the participants in this study. However, I realise that what I was trying to achieve was not possible, as the care setting did not have the structure in place to support DCM. This raises questions about the usefulness of DCM within the current climate. Although from this research it seems to make staff feel better about the care they provide, it does not seem to make a huge amount of difference to staff and clients in the face of strong opposition (e.g. poor resources). I now appreciate that this is a far more complex area than I first envisaged, and I feel substantial changes will not occur until there is major investment into the care provision for people with dementia (e.g. staff recruitment, training and support to staff). However, whilst ageism exists within our society, I do question whether this situation will change considerably, although recent policy changes are encouraging. Further, I think that until there is a clearer idea of how to provide and measure care provision for people with dementia, progress will be hindered.

Implications for clinical psychology training

I have considered how I could have worked more effectively with the staff team and I realise I was probably ill prepared, and did not possess the skills of working with a complex system. I feel clinical training would benefit if it provided more training in this area, as I am sure this would be applicable within many other specialities. Further, I agree with a recent article in "The Psychologist" that clinical psychology training could place more emphasis on the psychological needs of older people to encourage psychologists to enter this field, as there is an increasing demand for psychologists in this area (Clare, Baddeley, Moniz–Cook & Woods, 2003). Incidentally, it was refreshing and encouraging seeing the topic of dementia in a mainstream journal.

Some personal learning

Conducting this research has been a very challenging experience and at times I thought I would not complete this journey. I have come to realise how difficult it is to conduct research within environments where there is so much that one is unable to control. This may offer some explanation for the paucity of research in this area. However, in terms of conducting research in the future, I feel I am much better equipped and I am not so daunted by the experience. I feel I have learnt a lot about the process of developing and carrying out a research project (e.g. planning, going through ethics, writing for publication). I also feel more able to read research papers critically, and I am far more questioning about the research methods used and the claims made. I particularly enjoyed my introduction to grounded theory and the initial stages of data analysis. Although, I found this very overwhelming I also thought it was very creative and exciting.

In spite of my disillusionment, I still feel enthusiastic about working with this client group professionally and, although I realise it is difficult to affect change, I am excited by the developments in the field. I also consider there to be a lot of talented individuals who are making very useful contributions. I feel clinical psychologists have important contributions to make to this area. More research is needed but, as I have discovered, this is a more complex area than I first realised. Many more expeditions may be necessary before deciding the usefulness of DCM and before achieving the goal of providing better care for people with dementia.

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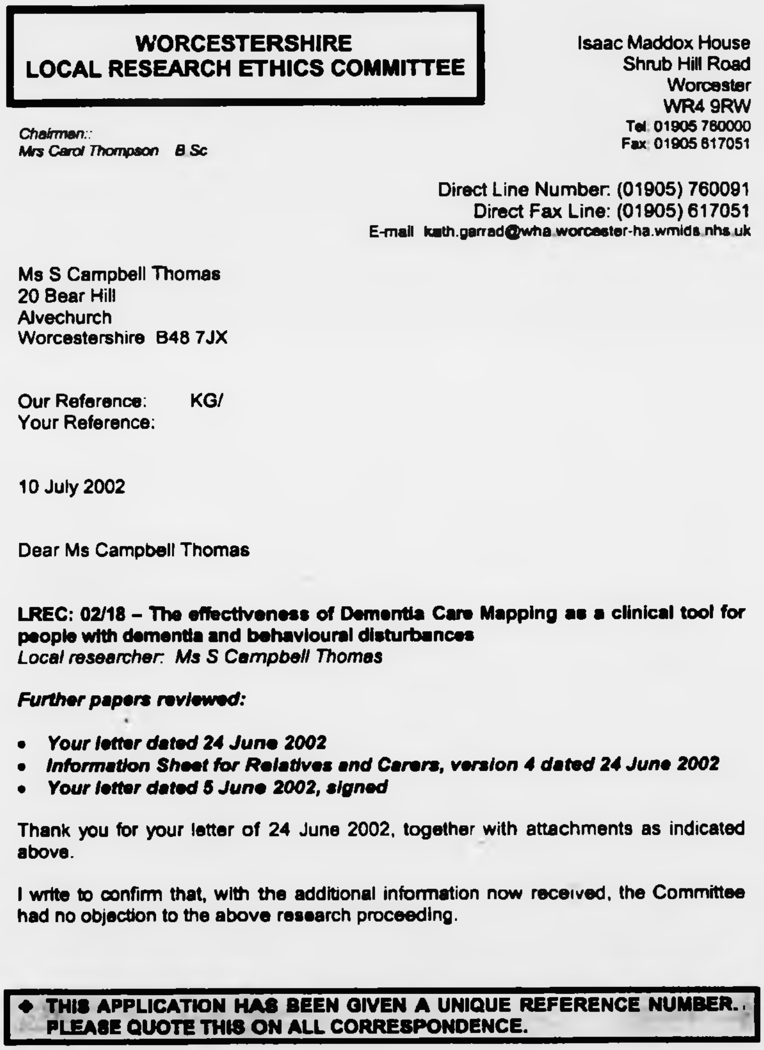
Appendix A

1. Ethical approval letter



WORCESTERSHIRE
LOCAL RESEARCH ETHICS COMMITTEE

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Ms S Campbell Thomas
20 Bear Hill
Alvechurch
Worcestershire B48 7JX

Our Reference: KG/
Your Reference:

10 July 2002

Dear Ms Campbell Thomas

LREC: 02/18 – The effectiveness of Dementia Care Mapping as a clinical tool for people with dementia and behavioural disturbances
Local researcher: Ms S Campbell Thomas

Further papers reviewed:

- ***Your letter dated 24 June 2002***
- ***Information Sheet for Relatives and Carers, version 4 dated 24 June 2002***
- ***Your letter dated 5 June 2002, signed***

Thank you for your letter of 24 June 2002, together with attachments as indicated above.

I write to confirm that, with the additional information now received, the Committee had no objection to the above research proceeding.

◆ THIS APPLICATION HAS BEEN GIVEN A UNIQUE REFERENCE NUMBER. PLEASE QUOTE THIS ON ALL CORRESPONDENCE.

Conditions of approval

- Satisfactory Indemnity arrangements being in place.
- You will no doubt realise that, whilst The Committee has no objection to the study on ethical grounds, it is still necessary for you to obtain approval from the relevant Clinical Directors and/or bodies in which the work will be carried out.
- In keeping with the Committee's protocol and in line with the Good Clinical Practice guidelines, would you please inform us of the results of the study when it is completed. If this is not within twelve months, please inform us of progress on an annual basis.
- Active approval is required until the study has been completed.
- Compliance with the Data Protection Act.
- The Committee would wish to be kept informed of serious adverse events, amendments and any other modifications to patient information sheets and patient consent forms.

ICH GCP Compliance

Worcestershire LREC is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Terms of Reference, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17th January 1997.

LREC Membership

Please find attached, for information, a list of members of the LREC.

If the project continues after THREE YEARS from the date of this letter Worcestershire Local Research Ethics Committee will wish to re-examine it.

Would you please communicate this approval immediately to all members of the investigating team and, where appropriate, the sponsoring commercial company.

Yours sincerely

Kath Garrad
Administrator, Worcestershire Local Research Ethics Committee

Enc: List of LREC members

2. Clinical Psychology Review - Guide for Authors

SUBMISSION REQUIREMENTS: All manuscripts should be submitted to Alan S. Bellack, Department of Psychiatry, The University of Maryland at Baltimore, 737 W. Lombard St., Suite 551, Baltimore, MD 21201, USA. Submit three (3) high-quality copies of the entire manuscript; the original is not required. Allow ample margins and type double-space throughout. Papers should not exceed 50 pages (including references). One of the paper's authors should enclose a letter to the Editor, requesting review and possible publication; the letter must also state that the manuscript has not been previously published and has not been submitted elsewhere. One author's address (as well as any upcoming address change), telephone and FAX numbers, and E-mail address (if available) should be included; this individual will receive all correspondence from the Editor and Publisher.

Papers accepted for Clinical Psychology Review may not be published elsewhere in any language without written permission from the author(s) and publishers. Upon acceptance for publication, the author(s) must complete a transfer of Copyright Agreement form.

COMPUTER DISKS: Authors are encouraged to submit a 3.5" HD/DD computer disk to the editorial office; 5.25" HD/DD di$ks are acceptable if 3.5" disks are unavailable. Please observe the following criteria: (1) Send only hard copy when first submitting your paper. (2) When your paper has been refereed, revised if necessary, and accepted, send a disk containing the final version with the final hard copy. Make sure that the disk and the hardcopy match exactly (otherwise the diskette version will prevail). (3) Specify what software was used, including which release, e.g., WordPerfect 6.0a. (4) Specify what computer was used (IBM compatible PC, Apple Macintosh, etc.). (5) The article file should include all textual material (text, references, tables, figure captions, etc.) and separate illustration files, if available. (6) The file should follow the general instructions on style/arrangement and, in particular, the reference style of this journal as given in the Instructions to Contributors. (7) The file should be single-spaced and should use the wrap-around end-of-line feature, i.e., returns at the end of paragraphs only. Place two returns after every element such as title, headings, paragraphs, figure and table call-outs. (8) Keep a backup disk for reference and safety.

TITLE PAGE: The title page should list (1) the article; (2) the authors' names and affiliations at the time the work was conducted; (3) a concise running title; and (4) an unnumbered footnote giving an address for reprint requests and acknowledgements.

ABSTRACT: An abstract should be submitted that does not exceed 200 words in length. This should be typed on a separate page following the title page.

KEYWORDS: Authors should include up to six keywords with their article. Keywords should be selected from the APA list of index descriptors, unless otherwise agreed with the Editor.

STYLE AND REFERENCES: Manuscripts should be carefully prepared using the Publication Manual of the American Psychological Association, 5th ed., 1994, for style. The reference section must be double spaced, and all works cited must be listed. Avoid abbreviations of journal titles and incomplete information.

Reference Style for Journals: Raymond, M.J. (1964). The treatment of addiction by aversion conditioning with apomorphine. Behaviour Research and Therapy, 3, 287-290.

For Books: Barlow, D.H., Hayes S.C., & Nelson, R.O. (1984). The scientist practitioner: Research and accountability in clinical and educational settings. Elmsford, NY: Pergamon.

TABLES AND FIGURES: Do not send glossy prints, photographs or original artwork until acceptance. Copies of all tables and figures should be included with each copy of the manuscript. Upon acceptance of a manuscript for publication, original, camera-ready photographs and artwork must be submitted, unmounted and on glossy paper. Photocopies, blue ink or pencil are not acceptable. Use black india ink and type figure legends on a separate sheet. Write the article title and figure number lightly in pencil on the back of each.

PAGE PROOFS AND OFFPRINTS: Page proofs of the article will be sent to the corresponding author. These should be carefully proofread. Except for typographical errors, corrections should be minimal, and rewriting the text is not permitted. Corrected page proofs must be returned within 48 hours of receipt. Along with the page proofs, the corresponding author will receive a form for ordering offprints and full copies of the issue in which the article appears. Twenty-five (25) free offprints are provided; orders for additional offprints must be received before printing in order to qualify for lower publication rates. All coauthor offprint requirements should be included on the offprint order form.

COPYRIGHT: Publications are copyrighted for the protection of the authors and the publisher. A Transfer of Copyright Agreement will be sent to the author whose manuscript is accepted. The form must be completed and returned to the publisher before the article can be published.

3. Ageing and Mental Health – Guide for Authors

Aging and Mental Health welcomes original contributions from all parts of the world on the understanding that their contents have not previously been published nor submitted elsewhere for publication. All submissions will be sent anonymously to independent referees. It is a condition of acceptance that papers become the copyright of the publisher. Books for review should be sent to Dr Chris Gilleard, Psychology Department, Springfield Hospital, Tooting, London SW17 7DJ, UK.

Manuscripts

Manuscripts may be in the form of: (i) regular articles (not exceeding 10,000 words); or, (ii) short reports for rapid publication (not exceeding 2,000 words). Four complete copies should be submitted to either Editor:Dr Mark Orrell, Department of Psychiatry and Behavioural Sciences, University College London, Wolfson Building, 48 Riding House, London W1N 8AA, UK. Tel: +44 (0)207 679 9452. Fax: +44 (0)207 323 1459, or Dan G Blazer, J. P. Gibbons Professor of Psychiatry and Behavioral Sciences, Duke University Medical Center, School of Medicine, Box 3005, Durham, NC 27710, USA.

All submissions should be in the style of the Publication Manual of the American Psychological Association (4th edition, 1994). Papers should be typed on one side of the paper, double spaced throughout (including the references), with margins of at least 2.5 cm (1 inch). All pages must be numbered.

The first page should include the title of the paper, first name, middle initial(s) and last name of the author(s), and for each author a short institutional address, and an abbreviated title (for running headlines within the article). At the bottom of the page give the full name and address (including telephone and fax numbers and e-mail address if possible) of the author to whom all correspondence (including proofs) should be sent. The second page should repeat the title and contain an abstract of not more than 200 words. The third page should repeat the title as a heading to the main body of the text.

The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content. Within the text section headings and subheadings should be typed on a separate line without numbering, indentation or bold or italic typeface.

Electronic Submissions: Authors should send the final, revised version of their articles in both hard copy paper and electronic disk forms. It is essential that the hard copy (paper) version exactly matches the material on disk. Please print out the hard copy from the disk you are sending. Submit three printed copies of the final version with the disk to the journal's editorial office. Save all files on a standard 3.5 inch high-density disk. We prefer to receive disks in Microsoft Word in a PC format, but can translate from most other common word processing programs as well as Macs. Please specify which program you have used. Do not save your files as "text only" or "read only".

References

References should follow APA style. All publications cited in the text should be listed following the text; all references listed must be mentioned in the text. Within the text references should be denoted by the author's name and year of publication in parentheses, e.g. (Woods, 1995) or (Mansell & McGill, 1995) or, if there are more than two authors, (Gallico et al., 1986). Where several references are quoted consecutively within the text the order should be alphabetical, e.g. (Elford & Sherr, 1989; Folkman, 1992). Similarly, where several references are quoted within a single year, the order should be alphabetical (Mansell & McGill, 1995; Woods, 1995). If more than one paper from the same author(s) and year is listed, the date should be followed by (a), (b) etc., e.g. (Blazer, 1995a).

References should be listed at the end of the paper in alphabetical order, typed in double spacing. Responsibility for the references and their verification against the original documents lies with the author(s).

References should be listed on a separate sheet(s) in the following standard form, capitalisation and punctuation:

a) for periodical articles (titles of journals should not be abbreviated):

WOODS, B. (1995). Dementia care: progress and prospects. Journal of Mental Health, 5, 115-124.

b) for books:

NORMAN, A. (1987). Aspects of ageism. London: Centre for Policy on Ageing.

c) for chapters within multi-authored books:

ROBERTSON, I. T. (1994). Personality and personnel selection. In C. L. COOPER & D. M. ROUSSEAU (Eds.), Trends in organizational behaviour (pp. 75-89). Chichester: Wiley.

Units of measurement

All measurements must be cited in SI units.

Illustrations

All illustrations (including photographs, graphs and diagrams) should be referred to as Figures and their position indicated in the text (e.g. Fig. 3). Each should be submitted on a separate sheet of paper, numbered on the back with Figure number

(Arabic numerals) and the title of the paper. The captions of all figures should be submitted on a separate sheet, should include keys to symbols, and should make interpretation possible without reference to the text.

Figures should ideally be professionally drawn and designed with the format of the journal (A4 portrait, 297 x 210 mm) in mind and should be capable of reduction.

Tables

Tables should be submitted on separate sheets, numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

Proofs

Proofs will be sent to the author nominated for correspondence. Proofs are supplied for checking and making essential typographical corrections, not for general revision or alteration. Proofs must be returned (by air mail or fax if overseas) within 72 hours of receipt.

Offprints

Fifty offprints of each paper are supplied free, to the nominated author for correspondence for further distribution, together with a complete copy of the relevant issue of the journal. Additional offprints may be purchased and should be ordered when proofs are returned. Offprints are sent approximately two weeks after publication.

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4. Dementia – Guide for Authors

1. The aim of the journal is to publish original research or original contributions to the existing literature on social research and dementia. When submitting papers for consideration, please attach a letter confirming that all authors have agreed to the submission, and that the article is not currently being considered for publication by any other paper or electronic journal.

2. Each paper submitted, if considered suitable by the Editors, will be refereed by at least two anonymous referees, and the Editors may recommend revision and re-submission.

3. *Length of papers.* Brief articles should be up to ....words and more substantial articles between ....and ....words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Please also supply an abstract of ...-..words, and up to five keywords arranged in alphabetical order.

4. When submitting a paper for consideration, our preferred method of receipt is as an electronic version and as a Microsoft Word document. This should be sent via email attachment to one of the Editors outlined in Note 18, together with a separate covering letter. If this is not practicable, please supply one paper copy and the article on a PC-compatible disk (containing text and all illustrations). Rejected papers will not be returned to authors.

5. Your typescript (written in English) needs to be typed using double spacing on one side only of white Aor US standard size paper, with generous left and right-hand margins (at least .cms) but without justification.

6. Your title page should give: one first name as well as the surname and any initials for each author; a maximum of four degrees/qualifications for each author and the current relevant appointment only; authors' accurate postal addresses; daytime telephone numbers, and fax and email numbers.

7. *Quotations.* Lengthy quotations (over ..words) should be displayed and indented in the text.

8. American or UK spellings may be used. Please use single quotation marks. Dates should be in the form 'May ....'. Delete full stops/periods from 'USA' and other such abbreviations.

9. If the paper is accepted for publication, a copy of the final version will be required as either an email attached Microsoft Word document, or on disk in a PC-compatible format. The author is responsible for ensuring that the final version of the article matches exactly the one required by the Editors.

10. *Tables.* You should present tables in your manuscript typed double-spaced on separate sheets and containing only horizontal rules. Each table needs a short descriptive title above it. Column headings should clearly define the data presented. If necessary, suitably identified footnotes should be included below. Take care to include all the units of measurement. The table needs to be cited in the text.

11. *Figures.* Line drawings should be presented as camera-ready copy on glossy paper (b/w, unless to be reproduced - by arrangement - in colour) and, if possible, on disk as EPS files (all fonts embedded) or TIFF files, ...dpi - b/w only. For scanning, photographs should preferably be submitted as clear, glossy, unmounted b/w prints with a good range of contrast or on disk as TIFF files, ...dpi.

12. *References in the text* should be presented in American Psychological Association (APA) style, i.e. the author's name and year of publication in brackets, together with the page numbers, e.g. 'As Kitwood (..., pp. ..-.) has observed', or, in a more general reference: 'Kitwood (...) appears to be saying ...'

13. *Reference list.* The references should be listed alphabetically in full at the end of the paper, typed double-spaced for ease of editing, in the following style:

Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society*, ..(), ...

Glaser, B. G., & Strauss, A. L. (...). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine.

Morse, J. M. (...). Emerging from the data: The cognitive processes of analysis in qualitative inquiry. In J. M. Morse (Ed.),

Critical issues in qualitative research methods (pp. .....). London: Sage.

Multi-authored articles: in the text, when the work has two authors, always cite both names every time. When there are more than two authors and less than six, cite all authors the first time and after that, just the surname of the first author and et al. The names of all authors should be given in the reference list.

14. *Language and terminology*. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used.

15. *Abbreviations*. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations

used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

16. The corresponding author will receive page proofs for checking. Twenty-five free offprints will be sent to the corresponding author, and each of the co-authors will receive a free copy of the journal.

17. *Copyright.* On acceptance of their paper, authors will be asked to assign copyright to Sage Publications Ltd, subject to retaining their right to reuse the material in other publications written or edited by themselves, and preferably due to be published at least a year after initial publication in the journal. Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere.

18. *Typescripts.* Authors should retain a copy of their typescript and send an identical electronic version as a Microsoft Word document, together with all figures and tables and a separate covering letter, via email attachment to:

Appendix B

1. The Alzheimer's Disease Related Quality of Life (ADRQL)

Alzheimer Disease Related Quality of Life™
(ADRQL™)

Interviewer: Read the following instructions aloud to the respondent.

Quality of life means how someone feels about different areas of his or her life. To find out about quality of life, people are usually asked to answer questions about themselves. Because of the effects of dementia, it is hard to ask people with this illness questions about their own lives. Instead, this questionnaire has been developed so that it can be answered by someone who spends time with and cares for a person with dementia.

There are several areas that make up a person's quality of life. I will briefly describe each area and then I will read statements about these. As I read each statement, please think about Mr/Mrs/Ms ___________ and whether the statement describes him/her over the last 2 weeks. If you agree that the statement describes Mr/Mrs/Ms ___________ over the last 2 weeks, please answer "Agree." If you disagree, because the statement does not describe Mr/Mrs/Ms ___________ over the last 2 weeks, please answer "Disagree."

Let me give you an example. I might read the statement, "He/She does not respond to his/her own name." If this statement describes Mr/Mrs/Ms ___________ over the last 2 weeks, you should say "Agree." If the statement, "He/She does not respond to his/her own name," does not describe him/her in the last 2 weeks, you should answer "Disagree." Do you have any questions?

Interviewer: Pause, respond to any questions and finish reading these instructions aloud.

I am going to begin the questionnaire now. Please tell me if you want me to speak louder, slow down, repeat a statement or stop so you can think about a statement. Also let me know if you want me to review the instructions.

Interviewer: Read aloud the introductory statements and each item exactly as they are written in sections A-E below. Place an X in one box to the right of each item in the correct response column.

A. These statements are about relating to and being around other people. After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms ___________ in the last 2 weeks or answer "Disagree" if it does not.

			AGREE	DISAGREE
A1.	He/She smiles or laughs when around other people	A1.	☐	☐
A2.	He/She does not pay attention to the presence of others	A2.	☐	☐
A3	He/She will stay around other people	A3	☐	☐
A4	He/She seeks contact with others by greeting people or joining in conversations	A4	☐	☐
A5.	He/She talks with people	A5.	☐	☐
A6	He/She touches or allows touching such as handshakes, hugs, kisses, pats	A6.	☐	☐
A7.	He/She can be comforted or reassured by others	A7	☐	☐
A8.	He/She is not comfortable with strangers or people he/she doesn't recognize	A8.	☐	☐
A9.	He/She reacts with pleasure to pets or small children	A9.	☐	☐
A10.	He/She talks with people on the telephone	A10.	☐	☐
A11.	He/She becomes upset or angry when approached by another person	A11.	☐	☐
A12.	He/She pushes, grabs or hits people	A12.	☐	☐

B. These statements are about a person's special identity and important relationships. After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms ___________ in the last 2 weeks or answer "Disagree" if it does not.

			AGREE	DISAGREE
B1.	He/She talks about or still does things related to his/her previous work or daily activities	B1.	☐	☐
B2.	He/She is aware of his/her place in the family such as being a husband/wife, parent, or grandparent	B2.	☐	☐
B3.	He/She makes or indicates choices in routine daily activities such as what to wear, what to eat, or where to sit	B3.	☐	☐
B4.	He/She becomes upset by personal limitations such as forgetting, losing things, or getting confused in familiar places	B4.	☐	☐
B5	He/She shows interest in events, places or habits from his/her past such as old friends, former residences, church or prayer	B5	☐	☐
B6.	He/She does not respond to his/her own name	B6.	☐	☐
B7.	He/She does not express beliefs or attitudes that he/she always had	B7.	☐	☐
B8.	He/She indicates "yes" or "no" by gesturing, nodding or talking	B8.	☐	☐

(Continued on back.)

C. These statements are about different types of behavior in the last 2 weeks. After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms __________ in the last 2 weeks or answer "Disagree" if it does not.

			AGREE	DISAGREE
C1	He/She smiles or laughs or is cheerful	C1.	☐	☐
C2	He/She squeezes, twists or wrings his/her hands	C2.	☐	☐
C3.	He/She throws, hits, locks or bangs objects	C3.	☐	☐
C4.	He/She calls out or yells or curses or makes accusations	C4.	☐	☐
C5.	He/She locks or barricades himself/herself in his/her room/house/apartment	C5.	☐	☐
C6.	He/She is irritable or easily angered	C6.	☐	☐
C7.	He/She says he/she wants to die	C7.	☐	☐
C8.	He/She cries, wails, or frowns	C8.	☐	☐
C9.	He/She shows delight	C9.	☐	☐
C10.	He/She is restless and wound up, or repeats actions such as rocking, pacing, or banging against walls	C10.	☐	☐
C11.	He/She resists help in different ways such as with dressing, eating or bathing, or by refusing to move	C11.	☐	☐
C12.	He/She clings to people or follows people around	C12.	☐	☐
C13.	He/She appears to be content or satisfied	C13.	☐	☐
C14.	He/She talks of "feeling sick", "having pain" or "being cold"	C14.	☐	☐
C15.	He/She shows a sense of humor	C15.	☐	☐

D. These statements are about usual activities in the last 2 weeks. After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms __________ in the last 2 weeks or answer "Disagree" if it does not.

			AGREE	DISAGREE
D1.	He/She enjoys doing activities alone such as listening to music or watching TV	D1.	☐	☐
D2.	He/She does not take part in activities he/she used to enjoy, even when encouraged to take part	D2.	☐	☐
D3.	He/She sits quietly and appears to enjoy the activity of others even though he/she is not actively participating	D3.	☐	☐
D4.	He/She shows no signs of pleasure or enjoyment when taking part in leisure activities or recreation	D4.	☐	☐
D5.	He/She dozes off or does nothing most of the time	D5.	☐	☐

E. The last statements are about behavior in a person's living environment. After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms __________ in the last 2 weeks or answer "Disagree" if it does not.

			AGREE	DISAGREE
E1.	He/She gets enjoyment from or is calmed by his/her possessions or belongings	E1.	☐	☐
E2.	He/She talks about feeling unsafe or says his/her belongings are not safe	E2.	☐	☐
E3.	He/She is upset or unsettled when in places other than where he/she lives	E3.	☐	☐
E4.	He/She makes repeated attempts to leave	E4.	☐	☐
E5.	He/She is upset or unsettled in his/her living environment	E5.	☐	☐
E6.	He/She is comfortable moving around where he/she lives	E6.	☐	☐
E7.	He/She talks about wanting to leave or go home	E7.	☐	☐

That concludes the questionnaire. Thank you very much for your help.

2. The Cohen-Mansfield Agitation Inventory (CMAI)

THE COHEN-MANSFIELD AGITATION INVENTORY - Long Form

lease read each of the 29 agitated behaviors, and circle how often (from 1-7) each was manifested by the resident during e last 2 weeks:

	Never 1	Less than once a week 2	Once or twice a week 3	Several times a week 4	Once or twice a day 5	Several times a day 6	Several times an hour 7
. Pace, aimless wandering	1	2	3	4	5	6	7
2. Inappropriate dress or disrobing	1	2	3	4	5	6	7
3. Spitting (include at meals)	1	2	3	4	5	6	7
4. Cursing or verbal aggression	1	2	3	4	5	6	7
5. Constant unwarranted request for attention or help	1	2	3	4	5	6	7
6. Repetitive sentences or questions	1	2	3	4	5	6	7
7. Hitting (including self)	1	2	3	4	5	6	7
8. Kicking	1	2	3	4	5	6	7
9. Grabbing onto people	1	2	3	4	5	6	7
10. Pushing	1	2	3	4	5	6	7
11. Throwing things	1	2	3	4	5	6	7
12. Strange noises (weird laughter or crying)	1	2	3	4	5	6	7
13. Screaming	1	2	3	4	5	6	7
14. Biting	1	2	3	4	5	6	7
15. Scratching	1	2	3	4	5	6	7

	Never 1	Less than once a week 2	Once or twice a week 3	Several times a week 4	Once or twice a day 5	Several times a day 6	Several times an hour 7
16. Trying to get to a different place (e.g., out of the room, building)	1	2	3	4	5	6	7
17. Intentional falling	1	2	3	4	5	6	7
18. Complaining	1	2	3	4	5	6	7
19. Negativism	1	2	3	4	5	6	7
20. Eating/drinking inappropriate substances	1	2	3	4	5	6	7
21. Hurt self or other (cigarette, hot water, etc.)	1	2	3	4	5	6	7
22. Handling things inappropriately	1	2	3	4	5	6	7
23. Hiding things	1	2	3	4	5	6	7
24. Hoarding things	1	2	3	4	5	6	7
25. Tearing things or destroying property	1	2	3	4	5	6	7
26. Performing repetitious mannerisms	1	2	3	4	5	6	7
27. Making verbal sexual advances	1	2	3	4	5	6	7
28. Making physical sexual advances	1	2	3	4	5	6	7
29. General restlessness	1	2	3	4	5	6	7

3. The Depression Rating Scale (DRS)

DEPRESSION RATING SCALE

(Research Institute of the Hebrew Home of Greater Washington)

1. How frequently does the participant seem sad or depressed? (Notice: sad face, slumped body, sad voice, crying, or verbalizations of sadness. Do not include agitation, physical complaints, sleep, or appetite problems.)

    1. Never
    2. Less than once a week, but still occurring
    3. Once or twice a week
    4. Several times a week
    5. Once or twice a day
    6. Several Times a day
    7. A few times an hour

2. How severe is the participant's depression when it occurs?

    1. Never occurs
    2. Very mild
    3. Mild
    4. Moderate
    5. Moderate to severe
    6. Severe
    7. Extreme

3. Rate the participant's ability to communicate (Item based on the Crichton Geriatric Behavioral Rating Scale, Robinson, 1961).

    1. Always clear and retains information
    2. Can indicate needs and understand information, though manifests some decline in level of expression or comprehension.
    3. Can indicate needs. Can understand simple verbal directions. Can deal with simple information.
    4. Understands simple verbal and non-verbal information but does not indicate needs.
    5. Requires much assistance or coaching to communicate.
    6. Cannot understand simple verbal or non-verbal information but retains some expressive ability.
    7. No effective contact.

4. How frequently does the participant engage in social activities (with residents, family, visitors, etc.)?

    1. Never
    2. Less than once a week, but still occurring
    3. Once or twice a week
    4. Several times a week
    5. Once or twice a day
    6. Several Times a day
    7. A few times an hour

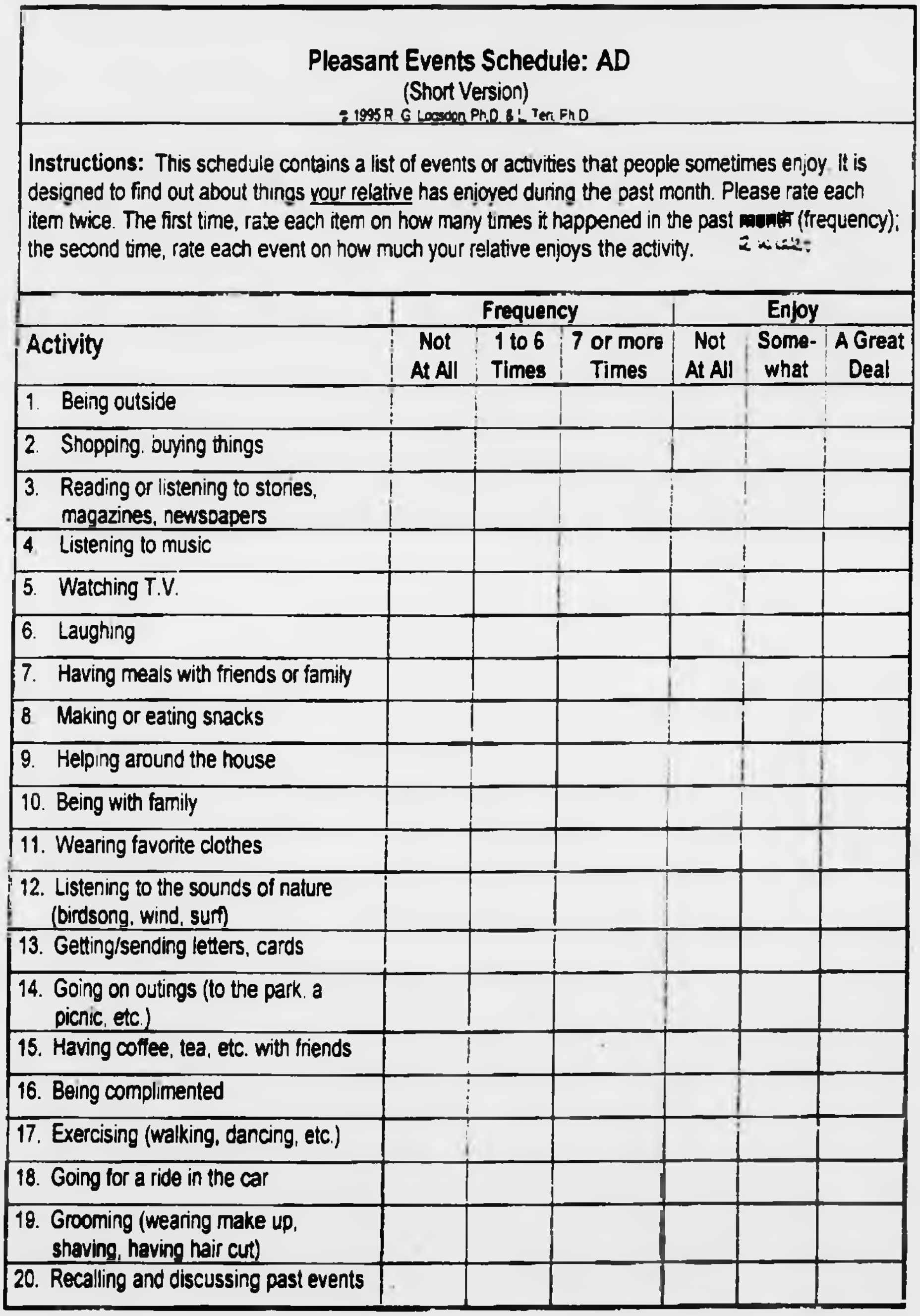
5. What is the quality of the social interactions the participant engages in?

    1. Always very negative, or abusive, or angry
    2. Frequently negative
    3. Sometimes negative (more frequently than positive)
    4. Usually indifferent or about equally positive and negative
    5. Sometimes positive
    6. Frequently positive
    7. Always positive, very warm

6. How frequently does the participant participate in activities (e.g., music, occupational therapy) or read, write, take a walk, or engage in any other activity which is meaningful for his/her level of functioning?

    1. Never
    2. Less than once a week, but still occurring
    3. Once or twice a week
    4. Several times a week
    5. Once or twice a day
    6. Several Times a day
    7. A few times an hour

4. The Pleasant Events Schedule (PES)



Pleasant Events Schedule: AD

(Short Version)

Instructions: This schedule contains a list of events or activities that people sometimes enjoy. It is designed to find out about things your relative has enjoyed during the past month. Please rate each item twice. The first time, rate each item on how many times it happened in the past ~~month~~ 2 weeks (frequency); the second time, rate each event on how much your relative enjoys the activity.

Activity	Frequency			Enjoy		
	Not At All	1 to 6 Times	7 or more Times	Not At All	Some-what	A Great Deal
1. Being outside						
2. Shopping, buying things						
3. Reading or listening to stories, magazines, newspapers						
4. Listening to music						
5. Watching T.V.						
6. Laughing						
7. Having meals with friends or family						
8. Making or eating snacks						
9. Helping around the house						
10. Being with family						
11. Wearing favorite clothes						
12. Listening to the sounds of nature (birdsong, wind, surf)						
13. Getting/sending letters, cards						
14. Going on outings (to the park, a picnic, etc.)						
15. Having coffee, tea, etc. with friends						
16. Being complimented						
17. Exercising (walking, dancing, etc.)						
18. Going for a ride in the car						
19. Grooming (wearing make up, shaving, having hair cut)						
20. Recalling and discussing past events						

5. Dementia Care Mapping - Behaviour category codes

Behaviour category codes

Code	Memory cue	General description of category
A	Articulation	Interacting 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 prioritizing 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
X	X-cretion	Episodes related to excretion
Y	Yourself	Talking to oneself, or an imagined person; hallucination
Z	Zero option	Behaviours that fit no existing category

6. Dementia Care Mapping - The scale of well-being and ill-being

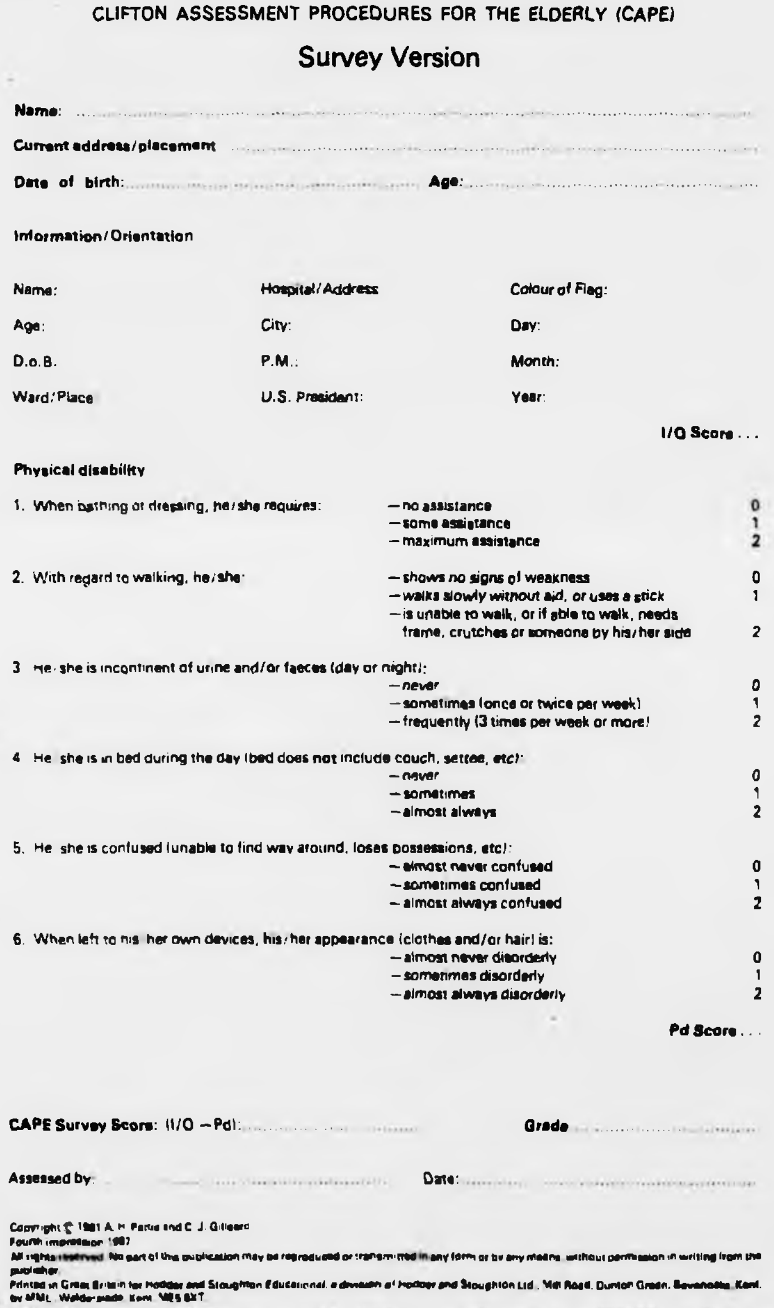
+5	Exceptional well-being – it is hard to envisage anything better; very high levels of engagement, self-expression, social interaction
+3	Considerable signs of well-being; for example in engagement, interaction or initiation of social contact
+1	Coping adequately with present situation; some contact with others, no observable signs of ill-being
-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; continued neglect for over half and hour
-5	Extremes of apathy; withdrawal, rage, grief or despair; continued neglect for over one hour

7. Dementia Care Mapping – The WIB score table for residential care homes

	Residential Care
Excellent	2.7 and above
Very good	2.1-2.6
Good	1.5-2.0
Fair	0.9-1.4
Much improvement needed	Less than 0.9

[Taken from the DCM manual (7th edition), Bradford Dementia Group, 1997]

8. The Clifton Assessment Procedure for the Elderly (CAPE)



CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY (CAPE)

Survey Version

Name: ....

Current address/placement ....

Date of birth: .... **Age:** ....

Information/Orientation

Name:
Age:
D.o.B.
Ward/Place

Hospital/Address
City:
P.M.:
U.S. President:

Colour of Flag:
Day:
Month:
Year:

I/O Score . . .

Physical disability

1. When bathing or dressing, he/she requires:
   - —no assistance 0
   - —some assistance 1
   - —maximum assistance 2
2. With regard to walking, he/she:
   - —shows no signs of weakness 0
   - —walks slowly without aid, or uses a stick 1
   - —is unable to walk, or if able to walk, needs frame, crutches or someone by his/her side 2
3. He/she is incontinent of urine and/or faeces (day or night):
   - —*never* 0
   - —sometimes (once or twice per week) 1
   - —frequently (3 times per week or more) 2
4. He/she is in bed during the day (bed does not include couch, settee, *etc*):
   - —never 0
   - —sometimes 1
   - —almost always 2
5. He/she is confused (unable to find way around, loses possessions, *etc*):
   - —almost never confused 0
   - —sometimes confused 1
   - —almost always confused 2
6. When left to his/her own devices, his/her appearance (clothes and/or hair) is:
   - —almost never disorderly 0
   - —sometimes disorderly 1
   - —almost always disorderly 2

Pd Score . . .

CAPE Survey Score: (I/O —Pd): .... **Grade** ....

Assessed by .... **Date:** ....

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Dependency Grade:

A — no impairment: independent elderly — comparable to those living without support in the community

B — mild impairment: low dependency — likely to include those needing some support in the community, warden-supervised accommodation and the better residents in residential accommodation

C — moderate impairment: medium dependency — people functioning at this level are likely to need *residential care or considerable support and help if at home*

D — marked impairment: high dependency — it is within this category that there is the greatest overlap between those in social services accommodation and those in hospital care

E — *severe impairment: maximum dependency — this level is seen most often in psychogeriatric wards* and the ones who remain in community homes/E.M.I. hostels often present considerable problems to staff in terms of their demands on staff time

Grades	A	B	C	D	E
I/O	12,11	10,9	8,7,6	5,4,3	2,1,0
MAb	11	10,9,8	7,6	5,4	3,2,1,0
Pm	12,11,10	9,8,7	6,5,4	3,2	1,0
CAS total	35-30	29-24	23-16	15-9	*8-0*
BRS total	0-3	4-7	8-12	13-17	18 -
Pc	0,1	2,3	4,5	6,7	8-12
Ac	0,1	2,3	4,5	6,7	8-10
Cc	0	0	0	1	2-4
Sc	0	1	2	3,4	5-10

Sixth impression 1986

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9. Staff information sheet

Dementia Care Mapping Research Project
Staff Information Sheet

Title of research study
The effectiveness of Dementia Care Mapping as a care-planning tool.

Introduction
A research project is being carried out on ******. The following information is for you to understand why the research is being done and what it will involve.

What is Dementia Care Mapping?
Dementia Care Mapping (DCM) is a way of evaluating and improving the care for people with dementia. DCM involves observing people with dementia to find out what the care is like from their point of view, as they often cannot tell us themselves. DCM finds out how the person with dementia spends their time, and whether they are in a state of well-being or ill-being. This means do they feel supported, valued and confident. The information from DCM is fedback to care staff to give them ideas of where the care they provide can be targeted to improve the patient's well-being.

What is the purpose of doing this research study?
The aim of this research project will be to find out whether the information provided by DCM helps staff devise care plans that improve patients' well-being, as there is little research evidence available at present.

Who is taking part in this study?
Dementia Care Mapping was recently carried out on ****** as part of the *********NHS Trust's audit project, to improve the care offered to patients with dementia. Four patients with the lowest well-being will take part in this study. They will be chosen following discussions with the ward manager.

What will the research study involve?
The main researcher will meet with staff at their Away Day to help then make changes to each participant's care plan based on the information received from DCM. Questionnaires will also be carried out to find out about each participants behaviour, mood, engagement in activities and their quality of life.

Next, the revised care plan will be put in place for one of the participants and the others will continue to receive the standard care.

After two weeks the main researcher will meet up with staff to repeat the questionnaires and to see how things are progressing. In addition, all four participants will be re-mapped using DCM.

Next, the revised care plan will be put in place for the next participant. Again after two weeks the main researcher will meet up with staff to repeat the questionnaires, to see how things are progressing and all the participants will be re-mapped. This process will continue until three participants have had their revised care plans put in place.

The care plans are introduced one at a time so we can compare the original and revised care plans to find out which is best, to see if DCM is a useful care planning tool to improve patients well-being. Also the fourth participant will not have any changes made to their care plan for this purpose. Finally, I will meet with some staff to find out what they think about DCM.

What will happen when the research study stops?
It will be up to the clinical team in charge of the patient's care to decide whether any changes to the care plans should continue.

What are the possible disadvantages and risks of taking part in this study?
Participation in this study may not improve the patient's well-being. If this study does lead to an improvement in patient's well-being, other patients' care plans will not be revised as part of this study.

What are the possible benefits of taking part in this study?
This research may contribute to future research to improve the care offered to people with dementia.

What will happen to the results of the research study?
They will be written up as a doctoral thesis, as part of the training requirements of the main researcher. They will be submitted for publication to appropriate journals. Patients and staff will not be identifiable in any report or publication. A summary of the results will be made available on the ward.

What if I want to know more information about the research study?
The main researcher is Sasha Campbell Thomas, Trainee Clinical Psychologist. If you wish to discuss any part of the study with me, please leave your contact details with the ward manager and I will contact you as soon as possible.

Many thanks for taking the time to read this information

10. Changes made to the care plans of Participants 2 and 3

Participant 2	
DCM findings	
DCM identified that interaction between P_2 and staff often resulted in "aggressive" episodes (e.g. he would push staff away). He was spending a lot of time on his own walking around the unit and moving furniture, and he lacked occupational activities and social interactions.	
Aims	
1) To make communication clearer and therefore increase positive interactions with staff 2) Redirection of "work like" behaviour into more meaningful tasks	
Plan of action:	
1) When communicating with P1:- • Use his preferred name • Approach him from an angle (as this is less threatening) • Gain his eye contact • Touch his arm or hand as a prompt • Ensure he is ready to speak (e.g. has he just woken up, • Check for background noise- • Direct talking to his left ear (as he is partially deaf in his right ear) • Speak clearly • Use simple, straightforward sentences– do not treat like a child • Use hand motions (if applicable) to make instructions clearer • Wait for a reply or response, this may not be immediate • If you get signs from him that he don't want to speak (e.g. turns away, pushes you away) don't keep trying to communicate. Tell him that you will come back later • When you judge that he is calm attempt to communicate with him again following the guidelines.	2) Attempt to engage him in activities. Examples include:- • Walk with him (outside if possible). Encourage engagement in the environment e.g. pointing out sights and sounds • Look through magazines/photos • Encourage him to take part in jobs within the unit e.g. drying dishes, folding clothes, • Carry out gardening task e.g. planting seeds. • Carry out wood work activities e.g. sanding wood

Participant 3

DCM findings

DCM identified that P_3 was spending a lot of time on her own in an isolated part of the unit. During these occasions she often appeared distressed e.g. shouting and screaming. The way staff approached her could either increase or reduce her distress. She often responded well to social interaction. Her agitated behaviour was greater during the afternoon, possibly as she was tired.

It was also observed that she required a lot of interaction from staff to motivate and maintain her well-being and was more distressed when alone. For example, when she is having a cup of coffee, she will get up and wander if she is on own. However, if she is with staff she will appear more relaxed and settled.

Aims

1) Increase meaningful interaction with staff and reduce social isolation
2) Reduce distress and agitation by helping her to relax and rest

Plan of action:

1) a. When a staff approach her:

- Speak her name and use eye contact to gain attention.
- Use a soft voice and short simple sentences (do not speak to her as if she is a child)
- If she is on the floor, offer her assistance to get up. Do not touch her without gaining her permission.

b. Staff are to try and spend regular amounts of time with her. Examples include:

- Sit with her, talking to her and holding her hand if she wishes.
- Jobs around the unit e.g. folding clothes
- Offering self care e.g. doing her hair or nails
- Looking at photographs

c. If she becomes distressed:

- Offer her comfort and reassurance to help her feel safe and secure (e.g. It is OK, you are safe). Try and offer her a task to distract her e.g. a walk or a drink. If she pushes you away leave her and return to her periodically, each time offering her comfort and reassurance.

2) Encourage her to relax throughout the day. Examples include

- Spending time with staff sitting and holding hands, talking, offering a hand massage.
- Offer her the opportunity for bed rest after lunch if she wishes. Stay with her until she is asleep. The nap should last for approximately 30 minutes. Check on her repeatedly during this time.
- Offer her a relaxing bubble bath in the evenings.

11. An example of a care plan progress form

Care Plan Progress Form

Name:...
Care Plan: Meaningful interaction and occupation with staff

Please complete this form at the end of each morning and afternoon shift

Date	Activity offered	Outcome rating (1-5)	Additional comments	Initials

Outcome rating (How did it go?)

1 = No interest or engagement at all
2 = Very little interest/engagement
3 = Joined in a bit, some interest/engagement
4= Joined in well with encouragement
5= A great deal of interest/engagement

Suggestions for additional comments

Communication – did (s)he initiate interaction (eye contact, touch) or conversation with you?
Did (s)he respond when spoken to, did (s)he need lots of encouragement?
Concentration –was (s)he able to concentrate and if so for how long, or was (s)he easily distracted
Enjoyment – how much would you say (s)he enjoyed the activity/time spent with you?

Appendix C

1. Dementia Care Mapping – Screening Questionnaire

Dementia Care Mapping

Questionnaire

The information provided in this questionnaire will only be used for the purpose of this research study and you will not be identifiable in anyway.

Personal information

Please complete the following to provide some details about yourself.

1. Name (optional)
Please complete if you have given permission to be interviewed

……………………………………………………

2. Sex: Male ☐ Female ☐

3. Age:
18-25 years ☐
26-35 years ☐
36-45 years ☐
46-55 years ☐
56+ years ☐

4. Staff Nurse ☐ Nursing Assistant ☐

5. Please indicate how long you have worked with people with dementia.

Less than a year ☐
1-3 years ☐
4-6 years ☐
7-10 years ☐
More than 10 years ☐

6. Please indicate if you have received any training in the following areas
(Tick all the boxes that apply)

Dementia care mapping ☐
Person centred care ☐
Dealing with challenging behaviour ☐
Communicating with people with dementia ☐
Offering activities to people with dementia ☐
Other(s) ……………………………………………………

Part 1 General views and experience

Please answer the following by ticking the most appropriate response.

1. Which one of the following statements most closely matches your overall view of Dementia Care Mapping?

I think it is extremely useful ☐
I think it is moderately useful ☐
I have no strong opinion ☐
I don't think it is much use ☐
I don't think it is useful at all ☐

2. How did you feel being observed during the Dementia Care Map?

Very comfortable ☐
Moderately comfortable ☐
Neither comfortable nor uncomfortable ☐
Slightly uncomfortable ☐
Very uncomfortable ☐

3. How did the Dementia Care Map affect your behaviour on the day?

I performed much better than usual ☐
I performed a little better than usual ☐
I performed as I usually would ☐
I performed a little worse than usual ☐
I performed a lot worse than usual ☐

4. How well do you think the information given during the Dementia Care Mapping Away Day reflects how the patients are coping on the ward?

Very well ☐
Quite well ☐
Not sure ☐
Quite badly ☐
Very badly ☐

5. How practical were the suggestions made from the Dementia Care Mapping Away Day?

Very practical ☐
Moderately practical ☐
Neither practical nor impractical ☐
Slightly impractical ☐
Totally impractical ☐

Part 2 Potential benefits and practical considerations

6. In your opinion, how beneficial overall were the changes made to the patient's care plans as a result of Dementia Care Mapping? **(Please tick the most appropriate response)**

Really beneficial	☐
Quite beneficial	☐
They made no difference	☐
Quite detrimental	☐
Really detrimental	☐

7. Please answer all of the following by circling the most appropriate response.

Since the Dementia Care Mapping Away Day and the introduction of the revised care plans:-

a) Are you interacting more with patients? **YES/NO**

b) Are you more aware of how you interact with patients? **YES/ NO**

c) Are you trying to carry out more activities with the patients? **YES/NO**

d) Do you feel you have a better understanding of the patients' behaviour? **YES/NO**

e) Please state below any other changes or differences you have noticed in your care practice since the Dementia Care Map Away Day and the introduction of the revised care plans.

....

....

8. Have you experienced any difficulties putting the revised care plans into practice?**(Please circle the most appropriate response)** **YES/NO**

a) If **YES**, what are the reasons for these difficulties? **(Please tick all the boxes that apply)**

I was too busy as there were not enough staff members on duty	☐
I had to deal with the needs of other patients	☐
Some of the other staff members couldn't see the point	☐
I got little or no response from the patients	☐
I was unsure what activities to try with the patients	☐

Other (s) ....

9. Please answer all of the following by circling the most appropriate response.

Since the introduction of Dementia Care Mapping to the ward:-

a) Do you enjoy working with the patients more than you did? **YES/ NO**

b) Do you feel more useful in your job? **YES/ NO**

c) Do you feel more stressed because of extra things you have to do with the patients? **YES/ NO**

Part 3 Additional comments

10. Please add anything else you would like to say about your views of Dementia Care Mapping that is not covered in this questionnaire including ways it could be improved.

2. Staff information Sheet and Consent Form

Dear

Re: Research into staff members' views of Dementia Care Mapping

As you may be aware, I am undertaking a research project on ******* House to complete my clinical psychology training. The research is concerned with finding out whether the information gathered from Dementia Care Mapping can help staff devise more effective care plans and thereby improve patients' quality of life.

As part of the study, I am interested in finding out about staff members' views of Dementia Care Mapping. Therefore, I would be grateful if you would complete the following questionnaire. In addition to filling in the questionnaire I would be grateful if you would complete some basic details about yourself. This should all take approximately 25 minutes and may be completed within working hours. **The information collected will remain confidential**. Once I have received the completed questionnaire, it will be necessary to interview a small number of staff to gather additional information. Interviews will be conducted in confidence at your convenience and within working hours.

Please indicate on the slip below if you are happy for your questionnaire to be used in this study. In addition, please indicate on this slip if you are willing to be interviewed. **You do not have to give permission to take part in this study and you may withdraw at anytime without providing a reason**. Please put the completed questionnaire and consent slip into the envelope provided, and place in the designated envelope in ********* office by **Friday 24th January 2003. Thank you very much for your time; your help is greatly appreciated.**

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I have read and understood the above, and
(please tick)

☐ I give permission for my questionnaire to be used ***confidentially*** in this study.

and

☐ I am willing to be interviewed ***confidentially*** as part of this study.

Signed:...

3. Dementia Care Mapping Interview Format

Usefulness of Dementia Care mapping
What do you think is useful/not useful about Dementia Care Mapping?

Experience of Dementia Care Mapping
What was it like being mapped?

How did it make you feel?

How did it affect you behaviour?

What did you think about the Dementia Care Mapping Away Day?

What did you think about the feedback provided on the Away Day?

What did you think about the action plans devised for patients?

In what way(s) has Dementia Care Mapping impacted on your care practice?

Has Dementia Care Mapping had any impact on how you feel about your job? If yes, explore in more detail.

Practical considerations
Have you experienced any practical difficulties putting the Dementia Care Mapping recommendations into practice? If yes, explore in more detail

Additional comments
Anything else you would like to add about your views and/or experience of Dementia Care Mapping?

4. Extract from transcript to illustrate open coding of the raw data

I = Interviewer R = Respondent

I What reason do you think the other needs are important?

R I don't think that sometimes the staff work as a team....some shifts are great and staff are enthusiastic and willing we all work as a team and everything can be covered ..but then there are staff who are old school if you like or have specific things they enjoy doing or what they will do and then it is not all shared to get every aspect of the patients needs covered *(implications of negative staff attitudes)*

I What reason do you think the occupational needs are important as well as the physical needs?

R Um.. the patients get lonely.. they get bored, frustrated……… *(patients feelings)*

I So, you felt the information was accurate and the most accurate bit really was that they were picking up that there was a real need for occupational needs? Do you think there is any information or ways that it didn't reflect how the patients are coping, any information you felt was unfair, or inaccurate at all?

R No, I just... the only thing I didn't agree with, I think, was the needs for more staff. I think that should be addressed as there are times in the day when you need more staff so that you can give each patient individual times to cover their occupational needs, because sometimes, you know, you're distracted and trying to do something (*implications of low staffing levels***). Each day is different, each shift is different, each hour is different and you can't keep trying things. It might not work one day – it can work another, (***variability of patients***) but then you're distracted.... You know...staff are limited....um....That's the only thing (***implications of low staffing levels***).**

I I understand that. Do they say that more staff are needed, or aren't needed?

R Is needed *(uncoded)*

I And you think there's not enough?

R Absolutely *(uncoded)*

I The information given on the day – any thoughts about how that could be improved?

R I would have liked to have known things beforehand that were going to be discussed, so you could think about it and sort of have questions to ask...so you're prepared *(Staff wanting more information)*

I Anything else to add about your thoughts or feelings about the Away day… anything else that springs to mind that was good or bad or that might be improved?

R I think in smaller groups you would have felt more comfortable (*Staff views about the DCM feedback day)*

I And what did you find practical about the suggestions given at the Away day? The suggestions that were given? What did you find practical about that?

R Well, I think with our client group, it's trying things out *(Trying different activities with patients)* **and I still don't think we've had chance to try many things out** *(need for more time)*. **What works for one person, you know...might not work for another person** *(variability of patients*). **It is about trying things out** *(Trying different activities with patients)*

I What sort of things that were suggested on the day that were practical and you feel you could try?

R Um...well, their occupational needs. Hand massages, and .... there was something said about cooking and that caused a bit of an uproar *(disagreement with DCM feedback)*.

5. Codes and categories with supporting raw data from transcript

Examples from transcripts	Code	Category
Puts why we do things. Why we sit in front of then when we feed them makes you aware why you do it, why look at them directly when talk to them. I know certain people have picked up learned why we do things learnt that from DCM. (c117-120) When somebody didn't explain they were putting an apron on him when they were feeding him I actually witnessed that and I thought on my god but it was too late, but it was good that they fed that back because I know that person did actually think about what they had done (c68-72)	Increases care staff's awareness of their care practice	Development and changes in care practice
I think sometimes it's just that somebody wants somebody to hold their hand, or maybe the music's annoying that person, or they're wondering where they are and they just need to communicate. I think it's all different. It's just …you know…looking deeper into it (k296-299). Now another patient….who paces…walks and walks. We thought he was quite happy doing that…you know…that's what that client does at that time and it was pointed out….no….that wasn't the case….. (k369-373)	Develops care staff's understanding of patients (behaviour)	Development and changes in care practice
I think it is useful in the fact you have an outsider comes in and they can pick up on things that you don't notice (c7-8).	Different viewpoint	Development and changes in care practice
Used to talk more in front of them…tend to talk more in private away from them so they don't feel they are being talked about (m182)	Privacy	Development and changes in care practice
Don't do all tasks, can sit down and talk to them better (m33)	Talking more with patients	Development and changes in care practice
We're using a light. A fibre optic light. Um…hand massage. Foot massage. We've found that one client really enjoys having her make up put on. This is something we've learnt from the Mapping You know…to try different things (k281-284)	Trying different activities with patients	Development and changes in care practice

Treat then like individuals rather than a group which is a lot better I find (m13). I think we've all been guilty of putting some music on…..oh I like this…..the staff like this…or we think this is appropriate and not thinking…what our clients enjoy and different clients enjoy different music (k275-279).	Treating clients as individuals	Development and changes in care practice
More conversation going on as regards to the individuals and what we are doing so there is more talking (m 124-125).	Increased communication of the staff team	Development and changes in care practice
Somebody to come in to teach us something different (m24)	Different way of doing things	Development and changes in care practice
I used to be so quiet and laid back and I used to think, well I'll wait until somebody says…. but now I just sort of want to do more (h252-253). Not frightened to try out new things. Just to try things (k387).	Staff taking more initiative	Staffs feeling in relation to their role
I enjoyed doing it trying to find occupational needs for people to do (c93). I am able to get the best out of the patients and able to teach other people that it doesn't all have to be a hard slog and task orientated it can be enjoyable (c203-204).	Staff enjoyment	Staffs feeling in relation to their role
Needed a bit more upsurge, which it (*DCM*) has given us (m25-26). It does help; over the year it gives people a kick up the bum because in a year you can slip into a lot of bad habits (c212-213).	Motivation	Staffs feeling in relation to their role
Improvement in the patients because of it (*DCM*). H laugh and smile at me when going well, I like seeing B relax when having her hands massaged. I like J talking to me when you when up to him. (c 99-c101).	Benefits to patients (some)	Staffs feeling in relation to their role
I think it's great that having more…. how can I put it, having more dealings with him, you know, being able to give him time, instead of …that's another one done and onto the next one. You know, you're able to actually sit with him now and interact. So it's better. (h231-234).	Enables staff to spend more time with patients	Staffs feeling in relation to their role

I think they should have appraisals, if things are going well – they should be appreciated (h308-310)	Recognition of staff	Staffs feeling in relation to their role
I still don't think we've had chance to try many things out (k136-137)	Need for more time	Staffs feeling in relation to their role
And that is where the OT can come in as well to be honest help us know what to try (c168-169)	Need for advice and support	Staffs feeling in relation to their role
I think that is something that our patient group really do need (*occupational needs met*)……. Sometimes it is quite easy to carry on with the physical needs and the other needs (emotional/occupational needs) are forgotten (k92-94)	Staff's views on the needs of the patients	Staffs' views of their patients
Each day is very different. What might works one day, doesn't work another (k174-176) Things just change and they change so rapidly that the Care Plan, it maybe worked for a couple of days and then literally it didn't have the same effect (k199-201)	Variability of patients	Staffs' views of their patients
No benefit for H as he has declined …. and J just gone from bad to worse… pacing about can't control him at all don't think it will be a benefit for him…don't think it has improved at all really (m141-143)	Deterioration in patients	Staffs' views of their patients
No not for J still the same…. B still the same as well….changed in a way sitting down more… otherwise hasn't changed (m150-151)	Benefits to patients (none)	Staffs' views of their patients
These patients don't have interest at all (m95)	Negative predictions of patient's response	Staffs' views of their patients
Um.. the patients get lonely.. they get bored, frustrated……… (k104)	Patients feeling	Staffs' views of their patients
Because I think this client group gets forgotten. Any suggestions for something that could help this client group –and to understand (k 394-396)	DCM promotes awareness and understanding of people with dementia	Staffs' views of their patients
Well, its just I feel uncomfortable. I have felt uncomfortable. I feel a little bit intimidated with my work when the mappers have been here. (H40-41)	Staff's experiences of the DCM observations	Limitations of the DCM method

Try and do your best but think did I say something wrong (c47-48).	Staffs perception of their performance during the observations	Limitations of the DCM method
I felt I was being intimidated in front of people and sort of pulled out in a crowd, I really didn't want to listen to any more….to be honest. (h144-146).	Staff 's views of the feedback day	Limitations of the DCM method
I think some of the younger ones felt more aware that they were there and put on the best but they didn't have to because they just do it naturally probably put on more of a show than they should have been (m79-81).	Staff s change in their behaviour during the DCM observations	Limitations of the DCM method
We have a lot of dealings with these patients and we should be more involved with the mappers and everybody else. (h163-166).	Staff wanting opportunities to give their point of view	Limitations of the DCM method
I didn't understand what this <u>mapping</u> was about anyway (h125-126).	Staff feel uninformed	Limitations of the DCM method
I would have liked to have known things beforehand that were going to be discussed, so you could think about it and sort of have questions to ask…so you're prepared (k125-127). Just a bit just to let us know what they were going to say what they were going to do for the patient…would have been a bit better for us (m136-137).	Staff want more information	Limitations of the DCM method
One patient did nothing for that two hours showed no interest in anything they were asleep soon as they left they were up laughing wanting to join in they missed out on all the good bits that we were doing and only saw the negatives so it is not very rounded in that respect.(c35-39).	Misinterpretation of the care environment and patients well-being	Limitations of the DCM method
Sometimes you need people (*mappers*) to come in before the DCM and get to know the patients spend time around them before you actually come in and judge them (c29-31).	Not enough knowledge of the patients	Limitations of the DCM method
It's good for them to have activities, I'm not saying to take them away, but there are certain activities that I don't agree with (*which were suggested at the DCM feedback day*) (h77-79). Mentioned giving P screws and stuff but I think he would have thrown them across the	Disagreement with DCM feedback suggestions	Limitations of the DCM method

floor and have no interest at all… (m97-98)		
To do the occupational needs of our clients with the staff level we've got I think is just impossible. Very difficult. Very stressful. I think if staff are stressed our clients are going to feel that (k149-151). As I said the staffing levels are low. Busy some days can't give them the individual care. Lot of agency staff trying to teach them what to do so not attending to the patients (m200-203). So much physical care is needed with our clients group and you've got two staff so it's very difficult. They're great ideas, but putting them into practice is very difficult (k156-159).	Implications of low staffing levels	Context in which trying to apply DCM
She (*another staff member*) hadn't been enthusiastic and she didn't want to know and I thought you know…..I'm fighting a losing battle here, so I found that difficult. Very difficult (k348-356). I think some staff have got a negative view of it (*DCM*) before they've tried something out. I think that makes it difficult to see if it really is working (k176-178). I have tried lets just sit down and have a coffee for 5 minutes with the patients and I get Oh I can't I haven't got time and you can't make people do things. I have tried to be nice about it and you can try to be firm and say you are doing it but people just resent you and you get no respect if you keep on. (c178-182).	Staff's negative attitudes to DCM	Context in which trying to apply DCM
Individually isn't a room for them to go haven't got individual space for them to go quietly and listen.(m208-209).	Limitation of the environment to providing individualised care	Context in which trying to apply DCM
I don't know what the answers is but it is a problem the old Barnsley Hall crew I think they have been in it too long and they are just tired and burnt out. (c182-184).	Staff's hypothesis about the reason for staff attitudes	Context in which trying to apply DCM
(*DCM encourages*) more of a homely feeling and having people who are more caring towards them. It helps them, it relaxes them and they feel safe with us. That's what I	Positive impact on the care environment	Context in which trying to apply DCM

like. (h290-293).		
Looking to see what we do with residents (m72-73)	Staffs understanding of the role of the DCM mappers	Did not fit into categories
I'm still in two minds with it (*DCM*) (h59, h69). I can't see there is anything that's negative about it…no…I think it's very good (k36-37).	Staff general views about DCM (ambivalent and positive)	Did not fit into categories