

Person centred dementia care: Problems and possibilities

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Abstract

Dementia care is an issue of increasing policy focus, with person centred approaches becoming synonymous with quality provision in this area. However, the implementation and efficacy of this approach is difficult to measure and in spite of trends towards evidence-based interventions, there are still huge variations in working practices. In order to address these issues the procedure of dementia care mapping has been developed. It aims to assess the wellbeing of people with dementia and other vulnerable groups through the observation of communal activities. With the use of dementia care mapping, this article will critically assess the implementation of a person centred approach with a group of care home residents. It will be shown that while participants potentially experienced many benefits from this approach and the social engagement and inclusion that derived from this, its efficacy and impact was undermined by factors that were often beyond the control of individual practitioners. Interventions aimed at promoting evidence-based practice and person centred care should therefore adopt a multi-levelled focus in order to address the wider group, organisational and social contexts that can facilitate or prevent its fulfilment.

Key words: person centred care, dementia care mapping, evidence-based practice, wellbeing.

Implications for practice

- Due to trends towards an ageing population, dementia is an issue of increasing relevance to policy makers and practitioners.
- Person centred care has become synonymous with quality provision in the area of dementia care and has been found to have generally positive impact on individual wellbeing and inclusion.
- The procedure of dementia care mapping has been developed to measure the implementation and impact of a person centred approach.
- Barriers to evidence based practice such as inadequate training, leadership and resources can undermine the implementation and efficacy of person centred care.
- Due to the diverse nature of these barriers, interventions aimed at addressing these should adopt a multi-levelled focus.

Introduction

The care of older adults with dementia is one of the fastest growing areas of need with the number of people with dementia in the UK forecast to increase by 154 percent over the next 45 years (Knapp et al, 2007). These demographic trends have been accompanied by increasing demands for the improved delivery of services for people with dementia (Department of Health, 2009), with person centred care becoming synonymous with quality provision in this area (Brooker, 2004). This person centred approach has been adopted as a core standard in

the National Service Framework for Older People (Department of Health, 2001). It provides an alternative to traditional task centred approaches which can promote client passivity and depersonalise the care giving process and can be seen as consisting of four overlapping elements (Brooker, 2004). These include valuing people regardless of their age and health status, treating them as individuals, emphasising their own perspectives and providing them with a positive social environment through the provision of meaningful activity and occupation. Such an approach conforms to the more general advocacy of 'active ageing' and its importance to the promotion of wellbeing and social participation in later life (WHO, 2002).

These developments in person centred care have been reflected in a number of recent research projects. For example, with regard to care home provision, research has been undertaken to prove the efficacy of a person centred approach (Fossey and James, 2008). One such study, by Chenoweth et al (2009) involved a randomised controlled trial in which a person centred care intervention was compared to usual care provision which utilised task centred approaches. It was found that the first approach lead to improved wellbeing such as reduced levels of agitation in the care home residents. This promotion of person centred care has been accompanied by a more general advocacy of the utilisation of evidence-based practices in health and social care, that is, practices for which there is consistent evidence that they improve client outcomes (HM Treasury, 2006). However, in spite of this commitment to person centred care

and the promotion of evidence based approaches (Fossey and James, 2008) there are still huge variations in working practices. This can give rise to unnecessary suffering to people with dementia and their carers through such things as the inappropriate administration of anti-psychotic drugs (All Party Parliamentary Group on Dementia, 2009) and a lack of social stimulation (Alzheimers Society, 2007).

In order to account for this continuing gap between evidence and practice, a number of explanations from different disciplinary perspectives have been put forward (Grol and Grimshaw, 2003). Firstly, cognitive and learning approaches focus on the availability and presentation of evidence. Secondly, behavioural and social influence theories focus on social norms and inadequacies of leadership, feedback, incentives, modelling and external reinforcement. Thirdly organisational and structural theories attribute barriers to knowledge utilisation to the wider environment in which the practitioner operates. Within the field of dementia care, these barriers are likely to be compounded by the under diagnosis of dementia as well as by the widespread assumption that little can be done to alleviate its impact. Difficulties in evaluating the implementation and efficacy of a person centred approach are also an issue, as people with dementia are often unable to fully express their own needs and preferences (Allan, 2001}.

In order to facilitate the implementation of person centred care and evidence-based practice, the procedure of dementia care mapping (DCM) is gaining

increasing popularity amongst researchers and practitioners (Brooker and Surr, 2005). It is usually performed in a group setting and is designed to assess, through the observation of day-to-day activities the nature and degree of well being experienced by people with dementia. It can also be used as an instrument for the development of person centred care practice (Kitwood, 1997). Firstly, on an individual level, information gained from mapping on the way in which residents spend their time and its relationship with their mood and engagement levels can be used to develop individual care plans. Secondly, on an organisational level, mapping can be used for such things as highlighting periods of staff shortages. Thirdly, DCM data can assist with staff development and resource management through such things as the examination of staff behaviour. A fourth way in which DCM can achieve practice development is through the monitoring and reporting of change over time.

It will be the purpose of this article to use DCM to assess the utilisation and efficacy of a person centred approach with a group of care home residents. Ways in which this approach can be facilitated and potential barriers to this facilitation will also be identified and discussed.

Methods

For the purpose of this study, five care home residents were selected to take part. While not all had a formal diagnosis of dementia they were all classified by the staff team as being at risk of having significant mental health problems or as

being vulnerable to social isolation and exclusion. All were female, their ages ranged from 77 to 92. One had a diagnosis of dementia, two had suspected dementia, one had a diagnosis of depression and one was physically frail. Ongoing consent was given for their involvement both by the resident themselves as well as by relatives and care home staff. One mapper observed participating residents over six-hour period. As these observations all took place in communal settings, the possibility of conducting an uninterrupted map was limited. Therefore a series of separate maps were carried out over a period of one week and on six different occasions. The activities observed included physical, intellectual or social components, which have all been identified as crucial to the promotion of wellbeing in later life (Cattan, 2009).

In accordance with the principles of dementia care mapping (Brooker and Surr, 2005), after each five-minute period or 'time frame', two types of codes were used to describe what had happened to each of the five participants. Firstly, behaviour category codes described the type of activity each individual was engaged in while being observed. Secondly, their mood and engagement level was recorded. This was expressed on a six-point scale ranging from minus five for extreme ill-being to plus five for extreme wellbeing and averaged to provide an overall ill-being/well-being score. The incidence of personal detractors and personal enhancers were also recorded. The former refers to staff behaviour that potentially undermines the person hood of participants while the latter refers to staff behaviour that potentially enhances personhood. These detractors and

enhancers are linked to five types of psychological need (Kitwood, 1997) including comfort, identity, attachment, occupation and inclusion.

Results

As it can be seen in table 1, the care home appeared to provide a stimulating and inclusive range of activities with leisure pursuits (49%) and exercise sessions (24%) being the most commonly occurring activities.

Table 1: summary of activities

Activity profile	Percentage of time
Leisure pursuits	49
Exercise sessions	24
Eating or drinking	9
Being engaged but passively watching	6
Interacting with others	5
Engaging in an expressive or creative activity	2
Walking	2
Receiving practical, physical or personal care	2

As shown in table 2, mood and engagement levels were also overwhelmingly positive for the observed group with only 2% of their time being spent in negative mood/engagement.

Table 2: summary of well-being and ill-being

Well-being/ill-being score	Percentage of time
-5: Very distressed. Very great signs of negative mood	0
-3: Considerable signs of negative mood	0
-1: Small signs of negative mood	2
+1: Neutral. Absence of overt signs of positive or negative mood	57
+3: Content, happy, relaxed. Considerable positive mood	39
+5: Very happy and cheerful. Very high positive mood	2

In addition, positive staff behaviour (enhancers) outnumbered negative behaviour (detractors) by a ratio of 13:4. There follows a summary of these enhancers (e) and detractors (d) over the six observations.

Observation 1: watching a show

The group were in the audience of a variety show.

- Occupation: facilitation (e) - Mrs A indicated to care workers that she would like to leave the main hall and was subsequently taken out in her wheelchair.
- Occupation: imposition (d) – as the performance had nearly finished, without consulting her, another care worker wheeled Mrs B out, in spite of the fact that Mrs B still appeared to be enjoying herself and people were still performing.

This highlights the way in which contextual factors can cause similar actions to have both positive and negative impacts and how, in the case of Mrs B, the needs and priorities of the care worker can predominate over those of the participant.

Observation 2: dining room

Residents were entering the dining room and starting to eat their lunch.

- Occupation: disempowerment (d) – Mrs A was wheeled into the dining room and positioned at a table. However, her wheelchair was positioned too far from the table to enable her to independently reach utensils and to eat her lunch without spilling it.
- Occupation: facilitation (e) – Another member of staff assisted Mrs A in repositioning herself at the table, provided her with her chosen lunch as well as with appropriate utensils and guidance.

This illustrates the need for carers to be aware of the individual needs of residents and to respond to these needs when providing support.

Observation 3: exercise session

The group were sitting in a circle in the main hall ready for the commencement of a ball throwing exercise.

- Occupation: facilitation (e) - the gym instructor asked Mrs B, to throw him a ball and as she was struggling to do this, his assistant provided Mrs B with appropriate help. She appeared to be pleased when the ball hit its target.
- Occupation: imposition (d) – similar assistance in ball throwing was offered to Mrs A, in spite of the fact that she was showing little apparent interest in the task and refused to cooperate.

These issues of facilitation on one hand and imposition on the other illustrate the fine line faced by care workers between providing appropriate support and providing too much support and the subsequent dilemma between care and control that can arise from this.

- Inclusion: fun (e) – Mrs C hit the instructor with the ball and he made a joke of it, causing amusement to most of the group, including Mrs C herself.

Observation 4: card game

The group were assembling in the activities room chatting and preparing to play a game of cards. When the cards were dealt, Mrs C helped Mrs B to assemble the cards in her hand.

- Occupation: facilitation (e) – a member of staff assisted Mrs B to play the card game as she was struggling to handle her cards. This action had a positive impact on her mood and engagement.
- Inclusion: supporting inclusion needs (e) – after Mrs D arrived in the room care staff made a great effort to make her welcome and include her in the ongoing games.

This shows the supportive role played by staff members towards Mrs B and Mrs D, while the actions of Mrs C illustrate the way in which group activities can facilitate mutual support between group members.

Observation 5: playing bingo

A large group of residents were assembled in the lounge playing bingo.

- Comfort: outpacing (d) – Although she did not attempt to communicate the need for help and continued to play, Mrs A appeared to be struggling to follow the game. For the benefit of her and the rest of the group, the facilitator rapidly explained the game and its rules, although Mrs A apparently still had problems and continued to struggle to keep up.

As the game continued it was clear that the facilitator was also struggling to run the session, as she was in sole charge of a large group and was helped by just one other member of staff who was moving around the group providing assistance to individuals. This helps to highlight how contextual issues such as staff shortages can undermine the quality of care provided. In addition, the issue of outpacing shows how the provision of a person centred approach can be

potentially compromised in a group setting due to the differing needs and abilities of individuals within the group.

- Occupation: facilitation (e) – Mrs A indicated to a care worker that she would like to go to the toilet and was subsequently assisted to do this and left the lounge.
- Attachment: acknowledgement (e) - as a member of staff began to assist her out of the lounge, she realised that Mrs B had been incontinent, she proved her with reassurance and empathy, telling her that she would take her back to her flat and help her to change her clothes.

Observation 6: exercise session

The group were assembling in the main hall ready for an exercise session.

- Occupation: collaboration (e) – the care worker assisting Mrs A into the room consulted her on where she would like to sit, placed her into her chosen position and ensured that she was sitting comfortably.
- Occupation: facilitation (e) – an assistant to the gym instructor sat with Mrs A to provide her with help in ball throwing. Mrs A appeared to enjoy the one to one attention and showed signs of positive mood and engagement throughout the rest of the session.
- Comfort: relaxed pace (e) – as Mrs B was struggling to keep up with a ball throwing exercise, the instructor adjusted his pace accordingly.
- Occupation: empowerment (e) – although Mrs E was slow in throwing the ball, staff did not intervene and just provide her with a few words of

encouragement. She proceeded to throw the ball and showed signs of a positive mood throughout the rest of the session.

- Identity: celebration (e) – the instructor celebrated Mrs E’s achievement with the rest of the group.

The adjustment of pace during the session highlights the way in which an awareness of the differing needs of participants can facilitate the provision of person centred care. While the group celebration of Mrs E’s ball throwing shows the promotion of group cohesion that can result from communal activities.

Discussion

There is much evidence to suggest that the observed care home does conform to the elements of person centred care, providing a positive and stimulating environment. With reference to mapping data, this is illustrated by the fact that mood and engagement levels were overwhelmingly positive. It is also shown by the great predominance of enhancing staff behaviour, particularly relating to the psychological need of occupation and by the high incidence of activity related codes in the behaviour category profiles. This involvement in activities has been widely recognised as being crucial to successful ageing which has been described as multidimensional, involving the maintenance of cognitive function as well as engagement in productive and social activities (Cattan, 2009). However, as mapping is normally conducted in communal settings, the observations reported here did not take place consecutively but focussed largely on structured activities taking place over a whole week. This may help to account for the fact

that the incidence of activity related behaviour codes was so high, perhaps giving an over optimistic picture of the incidence of meaningful occupation amongst residents (Packer, 2000a).

As its name suggests, a central feature of person centred care is the recognition of the needs and perspectives of the individual (Brooker, 2004). This approach was evident in the mapping exercise with staff regularly consulting with residents and displaying a prior knowledge of their needs and abilities, especially relating to the 'staff enhancer' category of 'facilitation'. This can be seen for example in the dining room (observation 2) when a carer adjusted Mrs A's chair at the table thus enabling her to reach her plate. However, in spite of the homes commitment to providing an individualised approach, this process, can easily exclude vulnerable groups such as those with dementia, who are often reliant on others for their needs to be recognised and addressed (Allan, 2001).

This exclusion can take place on a number of levels such as in their involvement in committees and review meetings. It can also take place in the 'hands on' support provided by care staff. For example, the mapping exercise revealed that the needs and priorities of Mrs B were subsumed to those of the carers who wheeled her out of the variety show earlier than she wanted (observation 1). Similar, imposition was experienced by Mrs A, when she was given assistance that she did not want during an exercise session (observation 3). This serves to highlight the dilemma between care and control faced by care staff. This

dilemma can be exacerbated by an organisational emphasis on maintaining resident's safety (Brooker, 2004) which can lead to a task-centred approach and the overprotection and subsequent 'institutionalisation' (Goffman, 1961) or relocation of more vulnerable residents. It is also compounded by high levels of staff turnover in care home settings and the increasing scale of such homes which means that staff are not always able to acquire a full knowledge of every resident and continuity of care is undermined (All Party Parliamentary Group on Dementia, 2009).

While dementia care mapping tends to focus on interactions between staff and residents, the context in which activities take place also has the potential to promote the wellbeing of participants (Manor, 1999) with group activities helping to enhance mutual cohesion and interaction (Vintner, 1967). This can be seen, for example, in the card game (observation 4) when Mrs C helped Mrs B in arranging her cards. It can also be seen in the exercise session (observation 6) in which members of the group joined Mrs E in her celebration of her success in ball throwing. However, while DCM requires the mapper to record all significant interactions between staff and residents, it does not require the detailed recording of interactions between residents. This can lead to an individualised focus and a subsequent neglect of mutual interaction which has been found to be major curative factors in group activities (Doel and Sawdon, 1999). In this respect, person centred care and the associated procedure of dementia care mapping can reflect the individualistic approach of community care policy and

social care practice. This is because it places great emphasis on individual need and the achievement of independence with little reference to the individuals relation to others (Phillips, 2001).

In spite of the potentially beneficial aspects of group activities, they can also compromise the provision of a person centred approach due for example to the differing needs and abilities of individuals within the group (Packer, 2000b). This can be seen in the bingo session (observation 5) in which Mrs A struggled to keep up, a situation that was compounded by apparent staff shortages (Packer, 2000b). Furthermore, as the care home did not cater specifically for people with dementia, residents with such a diagnosis or with other mental or physical disabilities were at particular risk of being stigmatised and marginalised amongst the wider resident group (Packer, 2000c). This issue of marginalisation is of particular relevance to group work in a care home setting where resident populations are increasingly diverse, with two thirds being estimated to have diagnosed or suspected dementia (Alzheimers Society, 2007). In spite of this high incidence, its prevalence tends to be underestimated with around two thirds of people with dementia not receiving a formal diagnosis (National Audit Office, 2007). This has led to a neglect of the need for workforce development in this area with primary reliance still tending to be on personal experience and past employment in a similar setting (Korczyk, 2004).

Even when training is provided it does not always include a dementia specific component, which experts agree should include a basic knowledge of dementia, person centred care and quality of life for people with dementia (Bowers, 2008). This neglect of dementia specific training is likely to be compounded by the assumption that nothing can be done to improve the wellbeing of such groups as well as by lack of regulation, resource constraints and the high turnover of care staff (CSCI, 2008) which further reduces the incentive of employers to invest in staff training. Moreover, while inadequacies in care are often attributed to skill deficits within the frontline workforce the role of management and leadership is equally important. Thus, organisational cultures which do not value good care can lead to staff frustration if training in good practice cannot be implemented (Bowers, 2008). In recognition of these issues, a number of policy initiatives have been recommended or implemented. Thus, the All Party Parliamentary Group on Dementia (2009) make a number of recommendations for change. These include responsive and ongoing mandatory training for care staff, well informed and skilled managers and the promotion of organisational cultures that facilitate the provision of good quality care. These recommendations correspond to the recommendations of the recently launched National Dementia Strategy for England (Department of Health, 2009) that aims to promote an informed and effective workforce for people with dementia.

In order to combat inconsistencies in this area, greater regulation is also recommended for training, training providers and service provision as well as

better integration between social and health care staff. These recommendations will be facilitated by policy developments such as the establishment of a new regulatory body, the Care Quality Commission, which will be responsible for regulating and inspecting all services in order to promote good dementia care. With specific regard to training, new qualification structures are emerging with the new Qualifications and Credit Framework Skills for Care. This will reform the existing set of National Vocational Qualifications and Vocationally Related Qualifications and facilitate the development of a dementia specific qualification pathway. As Brooker (2004) observes, societal prejudice towards people with dementia should also be addressed, for this gives rise to discrimination not only in the status, pay and training of dementia care workers but also in service provision and resource allocation. In order for this to be achieved, service providers should not only aim to maximise the quality and availability of support but should also focus on the advocacy and empowerment of the groups that they serve. Such processes are already apparent with trends towards an ageing population increasing the social influence of older age groups and putting older people's issues to the forefront of the political and policy agenda (Gilleard and Higgs, 2000). While thanks to the work of pressure groups such as the Alzheimer's Associations the rights of people with dementia are more recognised than ever before (Brooker, 2004).

Conclusion

This article has demonstrated the way in which person centred care helped to promote the wellbeing of a group of care home residents. It has also been shown how contextual factors such as staff shortages, inadequate leadership, training and regulation as well as the increasingly diverse needs of care home residents can potentially undermine these benefits. Further contextual barriers are apparent in the inherent ageism of contemporary society as well as in the dual jeopardy experienced by older people with a cognitive disability (Brooker, 2004). In order that these barriers are addressed policy and practice should not only focus on the promotion of a person centred approach. It should also focus on older people's role as active social participants (WHO, 2002) rather than as the passive recipients of welfare and on the multiple factors that can undermine their capacity to engage in this participation.

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