

Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff

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Aims and objectives. This article aims to describe the content of person-centred care as described by people with dementia, family members and staff in residential aged care.

Background. Person-centred care is increasingly being regarded as synonymous with best quality aged care; however, studies exploring stakeholders' experiences of person-centred care are few.

Design. A qualitative explorative design was employed using conversational research interviews and content analysis.

Method. Research interviews were conducted in 2007 and 2008 with staff working in aged care ($n = 37$), people with early onset dementia ($n = 11$), and family members of patients with dementia ($n = 19$) and were analysed using content analysis.

Results. The findings indicated that the core category of person-centred care was promoting a continuation of self and normality. Five content categories emerged as contributing to promoting a continuation of self and normality: knowing the person; welcoming family; providing meaningful activities; being in a personalised environment; and experiencing flexibility and continuity.

Conclusions. This study describes person-centred care as it is understood by people with dementia, their family members and staff in residential aged care, and as such it contributes with inside perspectives to current understandings of person-centred care, perspectives that have been largely lacking.

Relevance to clinical practice. The findings of this study are clinically relevant and ready to be operationalised and applied in clinical aged care. The categories can be used as a topic guide for discussions in aged care organisations on the quality of current care and as elements indicating how to increase the person-centredness of care provided.

Key words: aged care, Alzheimer's disease, dementia, nurses, nursing, person-centred care

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Introduction

Care provided to older people and especially those with dementia, in a person-centred way, is increasingly being regarded as synonymous with best quality care. A substantial amount of articles have been published in different nursing

and related journals during the last 10 years describing the content, effects and politics of person-centred care. However, person-centred care is still abstract and vague, partly as many publications are based on personal opinion, anecdotal evidence and/or theoretical constructs only. There is a dearth of empirical studies describing person-centred care as

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experienced by the various stakeholders. The aim of this study was to explore how person-centred care is understood and described by people with dementia, their family members and staff who work in residential aged care.

Background

Person-centred care is a concept that during recent years has become equivalent with best practice care (Ericson *et al.* 2001, Slater 2006). The concept of person-centredness in aged care originated with Kitwood who adopted the term from Rogerian psychotherapy and applied its meaning to the care of people with dementia (Rogers 1961, Kitwood 1997). In aged care, government departments around the world are becoming increasingly committed to ensure that the care is person-centred. The movement towards person-centred care is generally thought to have originated in the UK (Dewing 2004) and then moved across Europe and to Australia and North America. In Australia in 2003, for example, the Victorian Department of Human Services produced a policy titled 'Improving care for older people' where health services were encouraged to 'adopt a strong, person-centred approach to the provision of care and services' (DHS 2003). In academia, person-centred care has been the focus of many articles; however, a recent review described that there is still no consensus or explicit agreement on the definition of person-centred care, and further research is needed in defining the concept, developing and testing measurement tools, and conducting and replicating intervention studies (Edvardsson *et al.* 2008). The majority of available publications on person-centred care define the concept using personal opinion, literature reviews, anecdotal evidence and/or theoretical frameworks. For example, Brooker (2004, 2007) used the VIPS framework for describing person-centred care that consists of V – valuing people with dementia and carers, I – treating people as individuals, P – using the perspective of the person with dementia and S – a positive social environment. Even though this framework is helpful and makes sense, it is unclear on which empirical material it is based.

There are further examples in the literature where the base for explications of constituents and meanings of person-centred care is unclear. McCormack (2003) presented a conceptual framework for person-centred practices for older people, where person-centredness was premised on the concept of authentic consciousness. This framework is helpful in conceptualising factors that might enable person-centredness, but it was based on a research programme exploring the meaning of autonomy. Later on, this concept of authentic consciousness was merged with a framework of

caring (McCance 2003) to develop a person-centred nursing framework (McCormack & McCance 2006). Recently, the same authors used the caring dimensions inventory as an indicator of person-centred nursing (McCance *et al.* 2009). These are only a few examples where researchers aim to illuminate person-centred care by making it equivalent to other concepts, or where empirical data that support supporting arguments are lacking. However, most publications seem to agree that person-centred care is a multidimensional concept describing care that is based on and includes people's subjective experience of illness (Brooker 2004, 2007, McCormack 2004, Edvardsson *et al.* 2008, McCance *et al.* 2009). Critics of person-centred care contend that this concept is nothing more than a political slogan to identify a user-oriented approach to aged care (Packer 2003) and that the term has a too individualistic focus (Nolan *et al.* 2004). There are several specific clinical strategies described in the literature that promote person-centredness, and these include incorporating biographical knowledge in care (Clarke 2000, Clarke *et al.* 2003); reminiscence (Kontos 2005, Overshott & Burns 2006); validation therapy (Neal & Briggs 2000) and prioritising the quality of relationships ahead of completing tasks (Edvardsson *et al.* 2005, Sandman *et al.* 2006). There are also some intervention studies that have conducted so-called person-centred interventions in aged care that have had significant effects on residents (Sloane *et al.* 2004, Fossey *et al.* 2006) as well as on staff (Hoeffler *et al.* 2006). However, it remains somewhat unclear as to what specifically constituted person-centred interventions in these studies and how they were operationalised.

To conclude this brief synopsis, we cannot overstate the fact that, although the body of literature on person-centred care is accumulating, there is a lack of studies describing actual empirical findings where consumers and providers of aged care have been asked to convey what person-centred care is to them. This suggests that current understandings of the concept largely rest on abstractions, conceptual synergies and personal opinions. This article aims to describe the content of person-centred care as described by people with dementia, their family members and staff in residential aged care.

The study

Sampling and data collection

All data were collected in Victoria, Australia during 2007/2008. The sampling technique was based on convenience sampling, which meant that eligible participants were recruited from settings willing to participate in the study.

The data collection method also sought to achieve maximum variation by aiming to recruit participants from metropolitan and rural areas, who had experience from public and private settings in respite and residential care; some of whom had dementia; some of whom were caring for a family member with dementia and some of whom were staff working in residential care. The reason for including care providers, care recipients and their significant others was to receive narrations about person-centred care from multiple perspectives and from different contexts. As further described in Table 1, individual, focus group or telephone interviews were undertaken with staff working in residential aged care facilities ($n = 37$), people with early onset dementia who had had experience of respite care ($n = 11$), home carers of people with dementia ($n = 7$) and carers of people with dementia who lived in residential aged care facilities ($n = 12$). Focus group and telephone interviews were conducted for convenience purposes with participants from rural and remote areas. The informants were not known to the researchers prior to data collection, and all potential participants who expressed an interest in the study and met the inclusion criteria (experience of respite or residential care) by contacting the researcher, agreed to participate.

The study employed qualitative research interviews to obtain rich descriptions of person-centred care (Kvale 1996).

The interviews explored what the participants perceived to be person-centred care, the meaning of high-quality or low-quality care in residential facilities; experiences of respite or residential care and on what grounds a decision was made about which aged care facility was chosen as a place where the person with dementia would live. The face-to-face interviews/focus groups took place either in a private room in the aged care facility (staff) or the participant's own home. Interviews and focus groups varied in length between 45 minutes–two hours.

Ethics

The study was approved by the ethics committee of La Trobe University and the participating organisations. The researchers were aware that there were some ethical issues which needed to be considered in this study. The researcher (DF) collecting the data involving people with dementia was well cognizant of possible ethical considerations around vulnerability and competency. She therefore ensured that only those people were recruited to participate in the interviews, who understood both what the research involved and its implications and could provide informed consent. The researcher, a qualified nurse, ascertained at the time of the interviews that those people with dementia who were participating in the

Table 1 Description of participants, recruitment, settings and methods for data collection

Participants	Recruitment and settings	Data collection method
Residential care staff ($n = 37$)	Three residential care facilities were approached and informed about the study. One was a publicly run metropolitan facility, two were privately run rural facilities. The facility management informed staff about the upcoming focus group sessions. Staff who presented themselves at the sessions were re-informed about the study, and consent was obtained	Three focus groups
People with early onset dementia ($n = 8$) and carers ($n = 4$)	The study was advertised in the Alzheimer's Australia (AAV) newsletter. Two regional offices of the AAV who run support groups and social activities for people with early onset dementia responded with interest. The researchers attended the next group meeting to explain the study and recruit participants by obtaining consent Participants had experience of public or private respite care	Two focus groups. One focus group took place in a café where members of the support group regularly met, and the other group took place in the respite facility where the other group attended To start with, focus groups included only people with early onset dementia, and then carers successively joined the interview
People with early onset dementia ($n = 3$) and their carers/spouses ($n = 3$)	Interested people responded to a flyer in the AAV newsletter by phoning the researchers. These people were informed about the study, and consent was obtained Participants had experience of public or private respite care	Face-to-face interviews within a metropolitan area
Carers of people with dementia living in residential aged care facilities ($n = 12$)	Interested people responded to a flyer in the AAV newsletter by phoning the researcher, these were informed about the study, and consent was obtained Participants had experience of public or private residential aged care	Face-to-face interviews ($n = 5$) with those living in metropolitan areas Phone interviews ($n = 7$) with those living in rural areas

study were not being coerced to participate and she had the necessary skills to counsel participants should any of them become distressed by the interview or focus group process. None of the participants expressed any signs of distress during the data collection.

Data analysis

Transcribed interview texts were analysed according to the principles of qualitative content analysis (Graneheim & Lundman 2004), which aim to describe manifest content and/or interpreting for latent meanings of texts. The analysis was performed in three steps. A first open reading of the data as a whole was performed to grasp the content and gain a sense of what the texts were about. Secondly, the interview texts were read through and systematically divided into meaning units, which in the third step were analysed for shared content and abstracted into conceptual categories that mapped out the content of person-centred care as described in the interviews. These steps were jointly performed by three members of the research team (DE, DF and RN).

Findings

Our main findings indicated that the core category of person-centred care was 'promoting a continuation of self and normality'. The analysis further illuminated five content categories contributing to promote a continuation of self and normality; 'knowing the person'; 'welcoming family'; 'providing meaningful activities'; 'being in a personalised environment' and 'experiencing flexibility and continuity'. The core and content categories are presented in the following paragraphs and are highlighted and clarified by quotations. No identifiable information has been used to maintain confidentiality.

Promoting a continuation of self and normality

The participants' narrations suggested that the core of person-centred care was experienced as promoting a continuation of self and normality. Participants unanimously described how the progressive dementia eroded both conceptions of self-hood and the previously 'normal' life experienced by people with dementia and their families. All participants repeatedly described how good care, i.e. person-centred care, included aspects that supported the person with dementia in being the person they were and supported them and their family to continue with a life as normal as possible. Examples of such aspects of normal life included being addressed and acknowledged as a valuable and competent

person who people know and respect and being provided with opportunities to do likeable things and make decisions about when to get up from bed, what to eat and who to spend time with. The preservation of self and normality also involved being in familiar and flexible surroundings, spending time with family, having choices and the possibility to establish and maintain relations. The continuation of self and normality could from all the participants' perspectives be supported by a person-centred care consisting of the categories described below.

Knowing the person

All participants described knowing the history, preferences, needs, interests and particularities of the person receiving care as being fundamental in the provision of person-centred care. Participating staff felt strongly that it was not enough just to know the individual; this knowledge had to be translated into practice and actively used in the provision of care so that it could be person-centred. Knowing the individual was described as essential for initiating conversations, activities and routines that were meaningful for the person. Also, staff could, with such knowledge, provide small extras that the person enjoyed such as sitting in the sun, going for a coffee and/or doing a bit of gardening. Knowing the individual also included an awareness and understanding of their medical/health status and needs so that symptom management strategies could be individually developed, provided and evaluated. Graham, a family member described typically how knowing the person was a prerequisite for staff being able to satisfy his mother's needs and wishes:

Well it deals with the individual. For example, my mother is used to drinking lots of water not tea, coffee or cordial so it's about giving her what she wants. It's about attending to people's different food preferences and individuals' different ways of doing things.

Welcoming family

The family participants also described that welcoming them into the life and care of the person was another element central to person-centred care. Welcoming family was described as developing and maintaining trust in that the staff would actively communicate changes and significant events to the family; so that they did not have to constantly seek out information by making phone calls or asking the staff when they visited. Welcoming family was also described by staff as creating opportunities for beneficial teamwork, so that the family's unique knowledge about the person with dementia could be incorporated into care plans. Family member participants specifically expressed their need to feel

that staff actively encouraged them to maintain the relationship and life they had with the person even after the move into (admission to) an aged care facility. Sarah, who was interviewed together with her husband, explained representatively the importance of the family also being welcomed into the aged care facility care to avoid feelings of anxiety and being uninformed:

When it comes to the care of a loved one the communication has to be good – need to be told what is going on otherwise you won't be informed and then you feel really anxious and you don't understand what is happening.

Christina, whose mother lived permanently in a residential aged care facility, described how family should feel welcome at all times:

The family should be told that 'this is your mother's home so come and go as you please'.

Providing meaningful activities

All the participants, staff, family and persons with dementia, reflected that providing meaningful activities was another essential component of person-centred care. Individually targeted activities were described not only as providing a meaningful content to the day, but also as a means in reaffirming the residents as individual persons who were able to do the things they enjoyed. Family and staff further described that such activities preferably were adapted to the individual person's ability so that their self-esteem could be boosted by the successful completion of activities, rather than feeling defeated and demoralised by being expected to undertake something that was beyond their capability. The participants with dementia described how meaningful activities could provide feelings of being able to participate in and make a contribution to the life of oneself and others. Susan, the daughter of a woman in a residential care facility highlighted the significance of meaningful activities in fostering self-esteem and agency for her mother:

It is important to give mother the opportunity to perform tasks according to her ability, as if you don't use it you lose it. It also gives her the opportunity to keep up her self esteem as she feels like she can still participate in her life. I think that it still is important that she makes some small decisions like what she might wear for the day, as it doesn't really matter what she decides.

All participants agreed that person-centred care should include the opportunity to participate in parties, barbecues and celebrations of national events, as this created a dynamic, cheerful atmosphere of community, participation and 'an atmosphere of life' in the aged care setting. Family members

were very sensitive to what was happening in the environment, and several family participants narrated about places where nothing was going on and where residents just sat around. These places were described as horrible – somewhere where they would never comfortably stay themselves or move a family member into. Margaret, a carer who was interviewed together with her husband, described representatively for most family members how the presence of meaningful activities contributed to good, person-centred care:

I have played the piano in several residential aged care facilities and know the difference between a good place and a bad one. Some nursing homes you go in smell of urine and the residents just seem to be sitting around. In this one, even in the dementia ward, they are doing something and the staff are all so cheery and walking around with the patients. And they have such wonderful functions there and they have activities and make things. There is always something going on.

Being in a personalised environment

All participants touched on the importance of personalising the environment was a cornerstone in person-centred care. This involved enriching the environment with personal things like photographs, furniture, plants, decorations and other memorabilia that were either familiar to the person with dementia or that they were known to like. Family participants and staff described how such personal things could contribute to person-centredness in mainly four ways: by supporting the identity and continuation of self for the person residing therein; by functioning as meaningful conversation starters and areas for reminiscence between staff/family/residents; by enabling recognition and possibly also feelings of being at home in the setting and finally by reminding staff of the uniqueness of each person receiving care. Linda, a family member narrated how a personalised environment supported seeing the person behind the disease:

In the facility, the residents are able to bring in their own things, like their photos and pieces of furniture and this makes all the difference. When you walk into the room, you know something about the person by what is there.

Family members and participants with dementia also described how the aesthetics of the place had a part in person-centred care. Places that looked pleasant, with beautiful interiors, exteriors and surroundings were described as relaxing and comfortable. Also, views from windows or interior gardens were described as supporting feelings of being connected to nature, such aspects were important in homely and personalised environments. Alan, a participant with early onset dementia described characteristically what

homely meant for him and by that he illuminated the role of the environment in person-centred care:

Being homely means being able to look out the window and liking what you're looking at and inside you can have pictures on the wall and you can have your own bathroom and it feels like it is your own bedroom. Just normal things around you like a garden and animals, that's what I see as homely.

Experiencing flexibility and continuity

Mostly in data from staff and family, it emanated that to be person-centred, aged care facilities need to have flexible routines adapted to the person with dementia's needs rather than the needs of staff, especially in relation to staffing, care tasks and activities. Family members and participants with dementia further described that to be person-centred, staff had to be available and present. This included taking time for a cup of tea or to chat with residents and families. Furthermore, all participants agreed that being with residents had to be prioritised ahead of the completion of tasks in order to promote person-centredness. It was acknowledged that if tasks had to be performed, person-centred staff should make efforts to involve residents in the completion of the tasks to make them into meaningful moments. Lastly, family participants and participants with dementia identified that low staff turn-over with consistency in staffing was a prerequisite for the development of trust and relationship needed for person-centred care. Jean, whose father lived in a residential aged care facility, illuminated how consistency in staffing can facilitate familiarity:

There isn't a high staff turnover in my father's residential aged care facility and this is really good because even though he doesn't know their names he does recognise that he knows them and every now and then he will say something that shows that they are familiar.

Jean continued to describe how the focus of staff on being with the residents and taking time for a chat indicated good, person-centred care:

The staff are fabulous – they are caring, they always stop and talk, they are really attentive to my mother – they give her bits of information to make her feel that they care about her. They touch the residents, they hold their hands or in my father's case they put cream on his face when they don't know that you're there, they put their arm around him even for a few minutes and if they do these things when they don't know you're there then they do them all the time.

Discussion

The aim of this article was to describe person-centred care as perceived by people with dementia, family members and

staff in residential aged care. The findings add to current literature by providing insights into how consumers experience person-centred care and how staff can provide it. Previously, these perspectives have largely been missing in contemporary research literature. Traditionally, outcomes of person-centred care have been described as satisfaction with care and well-being (McCormack & McCance 2006), reduced prevalence of behaviours (Sloane *et al.* 2004) or reduced prescription of neuroleptic medication (Fossey *et al.* 2006). Our findings add an existential dimension to the understanding of what person-centred care is – 'promoting a continuation of self and normality'. As the progressive dementia with all its symptoms and limitations significantly threatens issues of self and normality, for both the person with dementia and their family, our findings are clinically applicable by suggesting ways that aged care staff can apply person-centred care to support both the life previously experienced as normal for the person with dementia and their family and their existential experiences of being a whole person rather than being reduced to a patient, a disease or a task.

The category 'knowing the person' mirrors what repeatedly is described as essential for person-centred care, for example, through the I – knowing the person – in VIPS (Brooker 2007). The category 'welcoming family' that emerged as a dimension of person-centred care extends the understanding of person-centredness to also include significant others as being the unit of care. This conceptual extension based on the experiences of people with dementia and their family members and staff is a welcome addition to the debate and understanding of person-centred care, as it addresses the criticism of person-centred care which claims that it is too individualised (Nolan *et al.* 2004) and that it neglects the family. As a comparison, the importance of including family into the care has been long established in palliative care where the whole family is seen as the unit of care (Ferrell 2005) and in aged care (Haesler *et al.* 2007) the importance of a constructive staff/family relationship has been noted. The needs of family in dementia care emerged in this study as a central component of person-centred care. 'Providing meaningful activities' also emerged in this study as a necessary component of person-centred care, and this category could be seen as an umbrella term describing person-centred processes (McCormack & McCance 2006). Activities promoting the good life of people with dementia have previously been described as being fundamental to quality care (Zingmark *et al.* 2002), and our findings confirm this. In addition, the importance of being able to contribute through activities is an aspect not previously found described in the literature, but emerged as an

important dimension of 'providing meaningful activities' that could promote a continuation of self and normality.

The category 'being in a personalised environment' touches on the social environment in VIPS (Brooker 2007) and also relates to the care environment described by McCormack and McCance (2006) as having a major impact on the delivery of person-centred care and can potentially support or obstruct person-centredness. This article adds an inside perspective of how being in a personalised environment can support the continuation of self for residents and how it also can function as a reminder for staff of the uniqueness of the person. Furthermore, our findings also highlight the importance of aesthetics and feelings of connectedness to nature in experiencing person-centred care. The last category 'experiencing flexibility and continuity' has previously been touched on from an organisational perspective (Cohen-Mansfield & Bester 2006, McCormack & McCance 2006). This category can add to the literature by reinforcing: the need for aged care providers to organise the care based on the needs of residents rather than needs of staff; that the completion of tasks should not come at the expense of being with residents and family; and that consistency of staff is essential for trusting the care as described by people with dementia and their family members.

Limitations of the study

The literature on qualitative content analysis describes that categories should be mutually exclusive, meaning that data should not fit into several categories (Krippendorff 2004), and this recommendation has been followed as carefully as possible. However, creating mutually exclusive categories was not always possible, something we believe is explained by the fact that human experiences are often complex and intertwined (Graneheim & Lundman 2004). It is acknowledged that the study represents experiences from a limited sample in selected settings, and further research is invited to further delineate the elusive concept of person-centred care and its meanings.

Although there is some debate about which concepts to use for assessing and describing rigour in qualitative research, concepts such as auditability, persuasiveness, credibility and applicability are generally viewed as important (De Witt & Ploeg 2006). Auditability involves providing information about the research process making the possible assessment of the rationale for and quality of the decisions made. Persuasiveness refers to the extent the work convinces the reader; if it 'rings true' as compared to readers' own life worlds. Credibility generally refers to the extent to which the findings can be confirmed by other work, or by the participants. Finally, applicability is commonly concerned with whether

the findings can be applied in settings other than those where they were uncovered (Sandelowski 1993, Schneider *et al.* 2003). The information provided about the research process together with how the findings are described and presented is the basis for readers' assessment of the rigour in this study. However, the rigour can be only partly established here and now, as credibility and applicability have a temporal aspect (Kvale 1996). This means that qualitative findings may also attain credibility and applicability if other researchers and clinicians use them in their own work, and hopefully this will be the case with our findings.

Conclusion and relevance to clinical practice

This article describes person-centred care as understood by people with dementia, family members and staff in residential aged care and as such it contributes an inside perspective to current understandings of person-centred care. The findings of this study are clinically relevant and ready to be operationalised and applied in aged care. The categories can be used as a topic guide for discussions in aged care organisations of the quality of current care and as elements indicating how to increase person-centredness of care provided.

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Contributions

Study design: DE, DF, RN; data collection and analysis: DE, DF, RN and manuscript preparation: DE, DF, RN.

Conflict of interest

None.

Disclaimer

The views expressed in this work are the views of its author/s and not necessarily those of the Australian Government.

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