

Care Perceptions among Residents of LTC Facilities Purporting to Offer Person-Centred Care*

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RÉSUMÉ

Cette étude a exploré d'une manière qualitative comment les résidents des maisons de soins de longue durée (SLD) pensent et s'adaptent aux soins qu'ils reçoivent. Nous avons interrogé et observé un groupe délibérément choisi parmi des personnes âgées dans sept établissements qui prétendent fournir des soins centrés sur la personne. Les descriptions interprétatives de la part de 43 entrevues personnelles avec 23 participants correspondaient à une réponse à la question: Comment les habitants perçoivent-ils les soins rendus dans les établissements de SLD qui se présentent comme offrant des soins centrés sur la personne? Trois thèmes dominants sont ressortis: (1) l'environnement bienveillant; (2) la préservation de la dignité; et (3) le maintien de l'autonomie personnelle. Les participants étaient sensibles à la charge de travail du personnel infirmier, mais se sentaient éloignés du personnel. Les participants ont donné des exemples de mauvais soins et une manque d'empathie, des indignités humains et des violations de l'autonomie personnelle causées par les politiques institutionnelles qu'ils se sentaient inhiber leur capacité à recevoir des soins selon leurs propres préférences. En général, ils ont contesté les allégations de soins centrés sur la personne, mais ils s'y sont adaptés pour faire face à un environnement qui menace leur dignité et leur autonomie.

ABSTRACT

This study explored qualitatively how residents of long-term care (LTC) facilities feel about and adapt to the care they receive. We interviewed and observed a purposeful selection of elderly residents in seven facilities purporting to provide person-centred care. Interpretative descriptions from 43 personal interviews with 23 participants answered the question: How do residents perceive the care rendered in LTC facilities purporting to offer person-centred care? Three themes emerged: (1) the caring environment; (2) preservation of dignity; and (3) maintenance of personal autonomy. Participants were sympathetic to the nursing staff's workload, but felt distant from the staff. Participants gave examples of poor care and lack of empathy, human indignities, and violations of personal autonomy caused by institutional policies they felt inhibited their ability to receive care based on their preferences. Overall, they challenged the claims of person-centred care, but adapted to cope with an environment that threatened their dignity and autonomy.

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There are widespread claims of a culture change over the past few decades from the traditional biomedical environment in nursing homes and other long-term care (LTC) facilities to more person-centred environments integrating housing with good personal and medical attention (Bishop & Stone, 2014; Bradshaw, Playford, & Riazi, 2012; Kane, 2010). This change is emerging from the belief that management of chronic disability should enhance personal independence, dignity, fairness, participation, and security (Division of Aging and Seniors, 1998), although evidence of improved health and quality of life for recipients is weak (Bishop & Stone, 2014; Hill, Kolanowski, Milone-Nuzzo, & Yevchak, 2011; Lee, Yu, & Kwong, 2009; Shier, Khodyokov, Cohen, Zimmerman, & Saliba, 2014; Zimmerman, Shier, & Saliba, 2014).

The philosophy of individualized person-centred care rather than institutional efficiency has had a strong influence on attempts to reform the culture of LTC by addressing the physical and psychosocial needs of residents and their families (McCormack & McCance, 2006). Person-centred care places the person, their values, and preferences at the centre of care to enhance each resident's autonomy, purpose, and meaning (Edvardsson & Innes, 2010; Koren, 2010). Successful reform to person-centred care depends on a cultural change throughout the organization by fostering positive and trusting relationships that attend to the needs and preferences of the residents, their family, and staff (Brownie & Nancarrow, 2013). Knowing residents as individuals with preferences, differences, and cultural identities that extend well beyond their medical status is a cornerstone of this change. To enable this wider understanding and foster supportive and trusting interactions in the facilities between residents, their families, and staff, administrators will permanently assign specific care-teams to individual residents. Administrators who ascribe to this philosophy of care attempt to provide staff with time and flexibility to focus on the needs and wishes of each resident. The objective also is to increase job satisfaction and reduce staff-turnover through supportive teamwork at all levels of the organization by ensuring that care-related decisions are shared by residents, their families, and staff (Tyler & Parker, 2011).

A national survey of nursing homes in the United States found recently that less than one-third (31%) of the homes had adopted either "completely" or "for the most part" the culture change to person-centred care (Doty, Koren, & Sturla, 2008). Practically, it is difficult to sustain such a focus in the midst of many conflicting priorities in LTC (Caspar, O'Rourke, & Gutman, 2009). Consequently, the biomedical model of practice prevails even where change to person-centred care was attempted (Campbell, 2014; Caspar et al., 2009; Lopez, 2006);

furthermore, administrators, nursing staff, residents, and their families each perceive this approach to care quite differently (Brownie & Nancarrow, 2013; Edvardsson, Fetherstonhaugh, & Nay, 2010; Hill et al., 2011; Rahman & Schnelle, 2008; Williams, Hadjistavropoulos, Ghandehari, Yao, & Lix, 2014; Wilson, 2008). A recent systematic search found only one study of person-centred care from the residents' perspectives, and it recommended qualitative case studies for further research on how residents assess their care (Brownie & Nancarrow, 2013). In summary, there is limited and inconclusive knowledge on how residents feel about the quality of care and quality of life in LTC facilities associated with culture change.

This article reports on interviews with and observation of residents living in LTC facilities that advertise person-centred care. Our objective was to answer the research question: How do residents perceive the care rendered in LTC facilities purporting to offer person-centred care? This question was addressed as part of a larger study exploring personal and environmental influences on the social integration of residents in LTC facilities. The aim of this article is to describe and reflect the perceptions of residents about the care they received, and their opinions on how organizational behaviour in the facilities influenced this care.

Methods

An analytical framework helped to guide our investigation by considering the physical environment, values, and norms of everyone involved, and the organizational structure of the facilities where the participants lived (Shier et al., 2014). We gathered and analysed all of the information following the principles of interpretive inquiry (Thorne, Kirkham, & O'Flynn-Magee, 2004) and constructivist grounded theory (Charmaz, 2000).

With approval from the local research ethics board we selected, in a large metropolitan area, a convenience sample of medium-sized (75–150 residents) facilities with websites or posters advertising the different models of person-centred care that they offered. One facility, which followed the Eden Alternative (Thomas, 1996) model, declared that it was "dedicated to providing individual care and respecting the whole person and striving for excellence in care". Another facility explained in its promotional literature that its "humanitarian ideals provide residents every opportunity to restore and maintain physical, mental, social and spiritual well-being". Others claimed to "promote and maintain a culture of resident-centred quality care"; or to "deliver person-centred care in a respectful, caring and responsible manner". Two of the facilities were owned publicly and the other five by joint

public-private ownerships. All of them advertised full-time residence, skilled nursing and personal care, meals, housekeeping, rehabilitation care, and recreational activities. One facility followed, as mentioned, the Eden Alternative (Thomas, 1996), whereas the other six developed “facility-specific” culture change models to guide their care. Each of these facilities offered permanent staff assignments, encouraged resident and family involvement in care planning, provided social opportunities for the residents to maintain relations with friends and family, allowed for the personalization of the resident’s private living space, and offered culturally diverse activities.

We recruited participants from the group of residents who had been living for at least one year in one of the seven facilities. Ethical requirements dictated the recruitment of participants indirectly through the staff of each facility. All participants were identified as frail by the investigator-interviewer based on medical records indicating that the individual evidenced at least three of the following conditions: recent weight-loss; exhaustion; weakness; limited walking speed; and low activity level (Fried et al., 2001). Staff also confirmed that all identified participants were cognitively alert without chronic confusion or dementia.

The investigator-interviewer experienced in interview techniques (Kvale, 1996) and Charmaz’s *constructivist grounded theory* (Charmaz, 2000) obtained an informed consent signed by each participant in advance of the scheduled interview, and conducted interviews privately and discreetly in a quiet area of the facility. She used written prompts from existing knowledge about person-centred care to guide the interview (Cohn, 2001; Franklin, Ternstedt, & Nordenfelt, 2006; Kahn, 1999; Lopez, 2006; Stolar, MacEntee, & Hill, 1992). She began the initial interview with each participant by posing the open-question: “Tell me about some of the things you like to do”. Later she prompted participants, if necessary, with the direct question “Tell me about the care you’ve received here”. The interviewer recorded the interviews on audiotape as well as made field notes and personal memos about the context and conduct of the interviews.

Interviews lasted between 30 and 120 minutes, and the interviewer transcribed each of them verbatim. After transcribing each interview, the interviewer met with at least one other member of the research group to discuss, clarify, or expand the themes emerging from a constant comparison and triangulation of information in the transcripts, field notes, and memos (Bowen, 2008; Charmaz, 2000; Fram, 2013; Thorne et al., 2004). The research group also discussed the objectives of the next interview. We continued with help from the staff to select participants until the themes seemed saturated

(Bowen, 2008). We felt that we could answer the research question after engaging 20 participants in 40 interviews, and we confirmed this feeling with three more participants.

We selected participants purposefully with the help of the staff in each facility to provide a range of positive and negative experiences relating to the care received, and completed a total of 43 interviews with seven men and 16 women (see Table 1). We used field notes written during and immediately after each visit to a facility to document the activities of the staff and residents over periods of at least three hours in each facility (Creswell, 2007). Most attention was directed to the culture and physical design of each facility to record interactions between residents and staff and between staff and management in public and private spaces. Our observational strategies were both passive and interactive whereby the investigator-interviewer attended the dining rooms and hallways to watch and participate in card games, sports, and other social activities throughout the day. However, in respect for the resident’s privacy, we did not enter their private rooms. Overall, in addition to interviews, we observed about 24 hours of social activity over several months.

Our analysis influenced by Barber’s theory of human relationships (Cohn, 2001) began during the first interview and continued while listening to, transcribing, and studying the other interviews, field notes, and memos. We used N-Vivo (QSR International Pty Ltd., Doncaster Australia) to embed codes and track themes in the transcripts. Although initiated by the interviewer, the analysis was supported by continuous interaction with other members of the research group, all familiar with the interpretive method, to avoid a bias in the selection of participants, to ensure that at least two members agreed on the open, axial, and selective codes ascribed to the transcripts, field notes, and memos, and to minimize the interpretive bias of the interviewer. We searched and organized each transcript for specific concepts (open coding), the essence of the concepts (axial coding), and the core concepts (selective coding) from the participants (Bowen, 2008). This process prompted a second interview with 10 participants and a third with five to clarify, confirm, expand, and saturate our interpretations. Eight participants died, were too ill, or moved to another facility before we could arrange follow-up “member-check” interviews with them.

Results

Three themes emerged from our analysis of the participants’ assessments of their experiences: (1) the caring environment, (2) preservation of dignity, and (3) maintenance of personal autonomy.

Table 1: Participants' pseudonyms, years in long-term care, personal characteristics, level of dependency, and size of facilities

Pseudonyms ^a	Participants					Facility	
	Years in Care	Sex	Age	Dependency ^b	Number of Interviews	Number	Number of Residents
Irene	5	F	89	P	2	1	130
Bonnie	5	F	88	I	2	1	
Meryl	2	F	78	I	2	1	
Penny	1	F	78	P	1	1	
Alice	7	F	84	P	3	2	80
Betty	1	F	89	D	3	2	
Clare	1	F	95	D	1	2	
Fran	6	F	78	I	2	2	
Nora	4	F	82	D	2	2	
Dean	1	M	86	I	1	2	
Monty	3	M	85	D	2	2	
Harry	1	M	68	D	3	2	
Gerry	4	F	88	P	1	3	148
Ed	2	M	97	D	2	3	
Ian	1	M	63	P	2	3	
Janice	5	F	93	D	3	4	75
Kate	1	F	83	P	2	4	
Olga	1	F	87	P	2	5	75
Quincy	10	M	58	D	3	5	
Ruth	1	F	78	D	1	6	75
Sara	1	F	97	P	1	7	130
Tina	2	F	94	P	1	7	
Ullie	1	M	81	P	1	7	

^a Names changed for anonymity.

^b D = dependent; P = partially independent; I – independent (From the Minimum Data Set 2.0; RAI-MDS 2.0).

Caring Environment

There were conflicting opinions about the caring environment of the facilities. Ullie praised the staff because

[t]hey keep you clean and look after you. Like I say, I never got looked after at home like I do here ... I don't think there are any [care-staff] in here who wouldn't go out of their way to help me if I need it.

Kate stated quite simply that “this is a beautiful place to live, the staff are number one”. Others were less enthused and tended to identify caregivers positively as compassionate or negatively as task-oriented. Tina, for example, explained that:

There are people built for this type of work and others who shouldn't be in it. The ones who are built for it, they love their people and look after them well, and share them with their other friends. And others that can't be bothered, just get it done and get away ... once in a while you want to say 'Why don't you go and get a job that you like?' You know, because they certainly don't like this one.

Harry echoed this description with the remark that: “if you don't like being in service to people, then

maybe you're in the wrong business”. Quincy wondered why the staff did not provide a more supportive and encouraging environment because he felt that “you get a lot more done with honey than with vinegar”. The differences in caregiving were quite apparent during observations. There were instances in each facility when residents who asked for help were ignored or told that “you're not mine, your person will be back soon”. Whether these responses from caregivers were due to lack of time, perceptions of responsibility, or just lack of care, usually the resident was not helped even though sometimes they simply wanted a sweater removed or a shoe adjusted.

Kate complained that it was difficult to ask for help from someone who was uncaring because, as she explained, “I'm not asking you 'cause I can, I'm asking you because I can't”. Others were anxious about the difficulty of asking for help under the threat of rejection.

I have this real bad pain and a bowel movement... I am so ashamed when I have to tell the caregiver... and she says 'AGAIN!' As if I enjoyed it ... however I can understand what she feels ... I'm ashamed that it happened; I'm ashamed that they have to clean it up ... I've always liked to be independent

and I can't be anymore and that's hard, very hard, because if you see any resistance in anyone you ask, you don't ever want to have to ask again. (Betty)

Quincy expressed the opinion that "it is a fine [line] between 'when do I complain?' and 'when do I keep my mouth shut and just accept certain things?'. Tina was particularly worried that her complaints might prompt the owners to close the facility "and sell us all to somebody else" because the owners might feel that "it is not worth it for the bits and pieces that they get out of it".

Meryl felt that her emotional needs were neglected and did not believe that speaking out would change anything:

I will be asking [the doctor] something and he has his hand on the door as if he is ready to go ... so it doesn't take many incidents like that for me to think what I have to say is not very important. People see the doctor because they have a broken leg or something, but he doesn't give a darn about my broken heart.

Nonetheless, participants generally seemed sympathetic to the workload and time constraints of the staff. Betty described how care aides are "only allowed so much time with each person ... I don't know whether it's 8 or 10 minutes". Ruth told us how she receives care from the staff only "if they got the time", whereas Sara described receiving care much like a bank: "[you] take it as it comes".

Specific teams of nurses and care aides were assigned to individual residents (i.e., permanent staff assignments) in all of the facilities, although participants felt that key decisions on care were made by administrators more often than by the assigned caregivers. An example of this apparent disregard for advice from the residents came from Tina who complained that "we have a box every week that we can put our suggestions in and the staff, they have the same thing ... [The suggestions] used to get followed through with, but they don't anymore". Mostly, we heard how the staff required approval from above for their actions, or that they were limited by institutional policies.

Preservation of Dignity

We observed residents being wheeled down the hallway, half-dressed, or wrapped in a sheet on their bath-day, or left sitting on the toilet naked with the door ajar, as a staff member sprayed air freshener with no apparent sensitivity to privacy or dignity. Maintaining personal dignity was a recurrent challenge for Harry:

One of the girls ... had me up in the [transport] sling yesterday ... while she is wheeling me up the

hallway, and I thought 'well, we're going to Harry's dignity room now.' [laughs] ... You're just sort of three quarters naked from head to toe with your privates hanging out and you're being walked up and down the hallway and you go 'how did this happen, that could have been avoided' ... I don't think your average person likes the idea of walking, being carried, or whatever in front of the general public, naked or half naked, no matter what the reason is. They keep you a little vulnerable at that point ... I don't know what you'd be afraid of, so it's not really straight-up fear. There's just something not quite right about this situation ... I'm hanging four and a half feet up in the air, going at whatever speed up and down the hallway. It is a little unseemly, I don't know how else to express it.

Alice described how "people are dragged down the hall in a lift with their diaper sort of hanging down, and you know dignity, kind of, is gone". She was upset also by an apparent disregard for personal identity:

If your relative is with you, they talk to the relative and they say 'well she has the odd back ache and etc., etc.' and when they do that to me I say, 'look, I am here, so talk to me.' ... I find it insulting; they talk above you like you are a mute, deaf and dumb ... They think we're all retarded and about to wet our pants at any moment and not having a brain in our heads ... It is true that there is such a stereotype about old age ... They talk to you like you are a child: 'oh that was so clever of you to tie your shoe like that, good boy' [laughing], or 'Oh mister so-and-so you're being so good today'. You know, I guess it's nicer than being awful.

The strongest discontent and even anger emerged during descriptions of policies relating to bathing and toileting. Ullie described how "they have their rules of course and they want to put you to bed at a certain time, they want to shower you on a certain day, bathe you on a certain day. So you have to cooperate."

A policy in all of the facilities allowed residents to have a bath or shower once a week and a daily wash with towels. Dean complained how he "tried to get a second [bath] a week, but the policy, they can't change it". Tina complained even more strongly: "I don't know any woman who wants to go without a bath for one week. I was quite horrified that we were only going to get it once a week". Olga hired a private attendant to help her because "I find it most important [to get] washed every day". Nora reacted initially to this policy with: "My God, a bath *once a week?!'*" but she told us how she became more accepting because "they wash under my arms, at least I think they sometimes do".

Displeasure with the policy on bathing paled by comparison to anger about the management of incontinence and "hygienic" pads. Clare described graphically how she came to terms with this problem:

I've always got pads on ... To begin with, I thought it was absolutely foul ... In the hospital they gave you the bedpan, but they don't give you that here. They don't approve of that, so what can I do ... you lie in your own filth, but then they come and take the dirty pad off, put a clean one on, and away they go again ... The routine is exactly the same for everyone.

Tina was more sympathetic:

They don't have enough nurses to get you up to go to the toilet, so they put these things on you ... so you have to put up with something ... it was hard ... and I said 'couldn't we have a bedpan?' Well, [chuckles uncomfortably] I've got them the odd time, but not very often. Well, now I'm used to it.

Each of the participants discussed instances in which their dignity or that of others was disregarded by the staff mainly due to the policies and rules by which they were abiding. Although there was discontent about these perceived indignities, the participants also described how each in their own way learned to cope with or accept the situation.

Maintenance of Autonomy

All of the participants complained about their loss of autonomy when staff imposed activities or care on them. Kate was incensed by her physiotherapist when, as she explained:

I get dizzy and my legs start shaking and I don't want to fall down and break something. So I've had an argument with our physiotherapist [who said] 'you should walk, you should walk more'. Well ... they're my legs and I know if I can stand up or not, and I told her 'get off my back', so she left me alone.

Harry took a strong adversarial position on challenges to his autonomy and independence:

There's a sense of hopelessness that occurs ... [when residents] can't do what they want anymore ... If you listen to a conversation between residents and staff ... the residents are never right, and their opinions are not worth anything ... [They] don't have any power and they're not happy about that 'cause they pay the bills, you know, and it's not cheap. It costs a lot of money here, you know, and it's like, all day long: 'stand up', 'sit down', 'turn around', 'do this', 'do that', 'do the other thing', kind of like you're being treated like you are [aged] 2 not 92.

Nonetheless, he too indicated a desire to avoid conflict with the staff:

"You have to go with it sometimes, whether you like it or not ... There is no reason to start a fight with the staff every night of your life just because

you don't agree with them, and they don't agree with you. So it's better for everyone if you just get along. So that's what we gotta do.

It was easier, he concluded, to acquiesce to the policies of the institution and the wishes or demands of the staff, but Harry and most of the other residents we interviewed were not happy about this, although each seemed to find a way to accept or rationalize their circumstance. Those who appeared to be more outspoken, or, as Tina indicated, "right up there with wealth and knowledge" and not "timid" like her, were more confident in their ability to maintain some sense of autonomy.

Discussion

This study of 23 older residents provides unusually frank and disturbing insights to the quality of life in all of the LTC facilities. Although we heard both positive and negative comments about the care received, the negative comments dominated and were focused mainly on the restrictions of institutional life and policies. Previous insights to similar facilities have come mostly from administrators and nursing staff (Brownie & Nancarrow, 2013) with little attention being paid to the voices of the residents themselves. Culture change is an amorphous term, so the interviewer did not refer to it directly or prompt the participants for stories of good or bad experiences. However, the negative perspectives all arose spontaneously, which might reflect a tendency for participants to take positive events for granted without much comment (Åberg, Sidenvall, Hepworth, O'Reilly, & Lithell, H, 2005).

Failure of culture change in LTC facilities has been blamed on regulatory, structural, organizational, and administrative constraints within facilities, all of which make improvements slow to establish and difficult to sustain (Burack, Reinhardt, & Weiner, 2012; Campbell, 2014; Rahman & Schnelle, 2008), as well as discourage emotional attachments between residents and caregivers (Rodriquez, 2011). Paperwork and other administrative activities allow staff little time for the social and personal needs of residents (Flesner, 2009). Indeed, the distress of overworked nurses was acknowledged sympathetically by participants. Typically, the nurses are less engaged with residents in a highly regulated organization (Colón-Emeric et al., 2010). Routine tasks purportedly encourage inertia and discourage the sensitivity of nurses and nurses' aides to uncontrollable events, such as toileting of residents. Our participants definitely felt disengaged from the staff members who they saw as burdened and preoccupied with routine tasks or other organizational activities. It was clear that several of our participants were discouraged by the organizational culture influencing the care they received.

Comparative case studies in Britain concluded that care-home residents are more likely to experience good care when front-line staff can work without administrative interference (Killett et al., 2013). However, several participants complained about a lack of shared aims between staff and administration. The British studies highlighted also the beneficial effects of administrators shielding residents from negative external pressures, such as Tina's worry about owners closing the facility because of her complaints. This and other worries draw attention to the difficulty residents feel adapting their personal defences to cope with anxieties, especially without a close emotional bond to the staff or a flexible environment with appropriate human, community, or social capital to bolster their resistance against adversity (Åberg et al., 2005; Dubbin, Chang, & Shim, 2013; Kitson, Marshall, Bassett, & Zeitz, 2013; Wild, Wiles & Allen, 2013). However, staff may be under similar restraints from whistle-blowing to raise concerns in official channels about poor practice and maltreatment of residents (Jones & Kelly, 2014).

Rodriquez (2011) asserts that the expression of emotions with some degree of autonomy contributes dignity to LTC relationships. Expectations of dignity in health care vary greatly and are conceptually confusing, but the human dignity expected by our participants was the Kantian dignity of self or of identity (Jacobson, 2007). They expect the rights of vulnerable people not only for what is done, but also for how it is done. They were offended, as Alice explained, by being treated altogether as if they were "mute, deaf, and dumb ... [and] retarded." Similar to findings from Edvardsson et al. (2010) on perceptions of care among older adults with dementia, "knowing the person" and avoiding stereotypes was an important aspect of caregiving aimed at maintaining dignity among many of our participants.

References in the interviews to social dignity echo reports from other institutions about time constraints and limited resources obstructing a basic standard of care (Coughlan & Ward, 2007; Rader et al., 2006). Lopez (2014) contended that nurses' aides in some nursing departments manage residents "behind closed doors" as "objects of labour" because of a bureaucratic orientation to efficiency. This apparent disregard for both human and social dignity is possible, he maintained, even in facilities purporting to provide person-centred care by assigning empathy peripherally to the more visible customer-oriented departments, such as the "activity department" where influential visitors are more likely to attend. Consequently, the impression of a humane person-centred culture change prevails in public spaces while residents are overpowered by staff for purposes of efficiency in the relative privacy of bedrooms and bathrooms. This impression

probably explains how Kate could reject the demands of the physiotherapist, whereas nobody could overcome the more intimate policies on bathing and toileting. People with functional disabilities maintain their dignity and personal integrity by retaining a sense of privacy, asserting the care they want and who should provide it, and adapting their expectations (Wadensten & Ahlström, 2009). Nonetheless, physical and emotional dependencies and violations pose formidable threats to personal dignity (Åberg et al., 2005; Franklin et al., 2006; Rodriquez, 2011), and this study throws more light on how residents manage these indignities with resiliency and resignation; as Harry said, "you have to go with it sometimes, whether you like it or not". Although the participants in general were incensed by the indignity that they experienced through being ignored, stereotyped, and treated as an object of care, each seemed to in their own way, cope with or at least rationalize the situations in which they found themselves. In this way, they demonstrated an inherent or learned ability to carry on in the midst of adversity.

Residents and staff in LTC are influenced strongly by the local culture and social behaviours, and frequently have conflicting ethical views on autonomy (Scott et al., 2003). Moser, Houtepen, and Widdershoven (2007) proposed that patients with chronic illness accept a loss of some autonomy, and that nurses lack clear ethical guidance on the extent of autonomy appropriate for each clinical situation. Nonetheless, concerns about personal autonomy and independence and the stigma of unwanted dependency can severely disturb self-image and life-satisfaction (Åberg et al., 2005; Lee et al., 2009; Ryvicker, 2009). The complaints about autonomy we heard were rooted in a North American culture of individualism, and focused mainly on the environment of poor or insensitive care rather than the personal affront of illness or disability. Participants recognized their dependency but felt that there was not enough done to encourage more personal control such as the desire to have a bedpan rather than an incontinence pad. Some participants more than others portrayed a firmer control of their autonomy and independence, possibly because they retained a positive outlook and sense of direction for managing their environment (McWilliam, Brown, Carmichael, & Lehman, 1994; Scott et al., 2003; Tu, Wang, & Yeh, 2006). Moreover, opportunities to voice their concerns, such as our interviews, might also give residents a comforting catharsis and enhanced their sense of autonomy and self-worth (Scourfield, 2007). It was clear that the men and some of the more outspoken women were able to exert more control over the care that they received and how it was delivered, yet in a person-centred approach all residents should be heard equally. From the participants'

perspective, the ability to be heard and have wishes attended to did not seem to be working as effectively as it could to support them.

Limitations

Our observations in the facilities confirmed much of what was said by the participants while the dominant themes echoed similar, if perhaps more positive, reports from residents in other facilities offering but not fulfilling the culture change to person-centred care (Åberg et al., 2005). The geographical distribution of the facilities was limited to one area, and the residents were all of European background and cognitively alert. Our selection was limited ethically by the advice of the staff on who could and might consent to an interview, although we did strive for maximal variation in responses and range of topics covered (Kirkevold & Bergland, 2007). Certainly this selection did not favour an overly positive view of the administrators' claim to person-centred care, but it probably precluded the less articulate and more reserved residents.

We approached the exploration with the aim of giving participants the freedom to talk about anything they wished with only minimal prompting to focus attention on life in the facility. We obtained detailed and coherent narratives or stories, and whenever possible we conducted follow-up interviews to clarify and expand the narratives. Unfortunately, there were participants who moved or died before we could arrange a follow-up. We did not test participants for cognitive acuity, so some participants may indeed have relayed fantasies during the interviews, although our observations in large part supported the participants' stories. It will be interesting, nonetheless, to interview people with mild to moderate dementia for their perceptions of care, dignity, and autonomy as the dementia worsens (Mozley et al., 1999). It would also be worthwhile to include the family member's perceptions of those with cognitive impairment due to the important role they have in person-centred care (Edvardsson et al., 2010).

Our approach to achieving saturation of information followed the usual principles of qualitative research, particularly the concept of cultural consensus in the context of culture change (Bowen, 2008). We kept this in mind as we analysed the interviews, and all of the indignities and loss of autonomy were corroborated by several residents and in many instances by direct observations of the interviewer. Nonetheless, we acknowledge that the guiding principles of saturation are arbitrary (Mason, 2010), and that further explorations are needed of care experiences in LTC, perhaps within other ethnocultural groups, to expand

the context of our findings (Browne, Mokuau, & Braun, 2009; Wild et al., 2013).

The objective of this exploratory study was to gain insight into the residents' feelings about care in a LTC facility. We did not seek the perspectives of the staff or the administrators beyond the physical observations made by the interviewer over a total of about 24 hours in the facilities, but we recognize that they may view their approach to care differently than our participants. Furthermore, we did not try to document the staffing levels or workloads, but we do appreciate how this can, as others have found, negatively impact the full implementation of person-centred care (Lopez, 2006). Certainly, future work is needed to better understand staff and administration perspectives as well as the influence of staffing levels, although that was not the focus of this study.

Implications for Theory and Practice

These stories of avoidance, resistance, and adaptation to adversity support the concepts of resilience and successful aging (Wild et al., 2013). They relay the process by which vulnerable people interact with their environment as they cope with the indignities of institutional life, violations of intimacy, and loss of autonomy. The complaints of the residents were both condemnations of false claims of person-centred care and evidence of a resilience and resistance to adversity. Their enthusiastic participation in our study revealed also a desire to tell their story as a means of managing or buffering the adversity of their environment (Gattuso, 2003; Nakashima & Canda, 2005).

The intensity of the descriptions and feelings expressed by some participants suggests that activity theory, with all the historical, cultural, and institutional concepts of power and authority, explains the concerns about care, dignity, and autonomy. The residents were engaged actively with institutional life and its restrictions as activity theory predicts (Lemon, Bengtson, & Peterson, 1972). They sought satisfaction from informal more than formal relationships with members of the staff. Their concerns could be explained also by the theory of harmonious aging so that everyone, as Harry said, can "just get along" (Liang & Luo, 2012). Indeed, the disharmony of residential care precipitated their anxiety and anger tinged with a desire, as Kahn (1999) found elsewhere, to "make the best of it". This all contrasts dramatically with the purported harmony of person-centred care seen on websites and posters, and adds context to the quest for a broader social structure to successful aging as people seek to thrive on their own terms (Martinson & Berridge, 2014).

A change of culture to person-centred care will not suit everybody (White et al., 2012). Moreover, the limitations

of change, whether from ignorance, inadequate regulation, staffing and management problems, or from lack of money, supports the view that claims of universal success of person-centred care may be misleading, and that failure to admit the difficulties of implementing and sustaining change erodes the movement's credibility (Rahman & Schnelle, 2008). On the other hand, many caregivers in residential care nourish and dignify the residents' need for close emotional relationships (Jacobson, 2007; McGilton & Boscart, 2007; Rodriquez, 2011; Wilson, 2008), and our participants offered further context to these relationships. Westerhof, van Vuuren, Brummans, and Custers (2014) explained how task-centred behaviours provide order and consistency while person-centred behaviours prevent "technocratic or bureaucratic professionalism". They show that subtle combinations of both can coexist in most caring relationships through the interactive agency of both parties. The subtlety and volatility of this interaction was relayed by our participants who saw both the good and the bad in their relationships with the staff. Unfortunately, they interpreted the relationships as unbalanced and overly task-oriented in many instances. This was particularly evident in our study with regard to the permanent assignment of care teams, which are designed to develop a trusting relationship. However, it seemed that this strategy can also have a detrimental impact when the premise behind this strategy is not well understood by those in direct care who see residents as "not theirs" and are therefore unwilling to help with needs when requested. As Nolan, Davies, and Brown (2006) suggested, a stronger focus on relationships will recognise and enhance everyone's contributions to the therapeutic environment of LTC.

The implications of our findings for public policy on the general regulation of LTC facilities call for more careful assessment of residents' needs and staff activities. However, governmental regulatory directives will not necessarily improve the quality of care and the dignity of the residents if health authority surveyors fail to inspect appropriately (Jiang & MacEntee, 2013) or when there are conflicting priorities regarding care within the facilities (MacEntee, Thorne, & Kazanjian, 1999). Regulations in Australia were enforced more effectively when there was a formal auditing and re-auditing of nursing activities in LTC (Georg, 2006). Policy needs to emphasize contextual sensitivity to the needs of residents, and acknowledge the limitations imposed by insufficient public funding in a climate of cost-containment and operational efficiency (Berta, Laporte, & Kachan, 2010; Koren, 2010).

The tensions between residents and staff indicate a strong need for improved communications within the facilities, but they revealed how nursing routines and time constraints, and possibly hidden quality assurance

systems, can distract from the intimacy of the social relationships between the residents and the staff. Providing more autonomy to the staff in the care they render without tight schedules could improve the quality of care by increasing job satisfaction and reducing staff turnover (Berta et al., 2010). However, the participants in our interviews pointed also to problems of staff competency and workloads along with a general lack of privacy possibly compounded by the physical design of the facilities. It should not be necessary to leave scantily clothed residents in public hallways waiting their turn for a weekly bath or shower. Policy on LTC would benefit also from attention to the design and technological provision of elder-friendly buildings appropriate for the diversity of participants, the expectations of multicultural communities, and the chronic uncertainty of health care funding (Shepley & Song, 2014; van Hoof et al., 2014). LTC facilities are not only places where residents receive care; they should be, above all, places where residents live safely, securely, and with dignity during the final stage of life.

Rahman, Applebaum, Schnelle, and Simmons (2012) advocated "Rogers' conceptual model for disseminating new knowledge" with its attention to innovation, social systems, communication channels, and time for disseminating the new knowledge. Even if culture-change is feasible, they contend, it can take months or years to implement in residential care, but as the residents in our study explained, innovation will be ignored in facilities that are underfunded, understaffed, and over-regulated. The enthusiasm of the participants in our study suggests, as did Shura, Siders, and Dannefer (2011), that the balance between the tasks and the person could be established and sustained by encouraging residents to express openly their concerns and anxieties. We heard several appeals to give residents and staff a voice to their concerns about the indignities and lack of personal autonomy in residential care. Addressing these concerns would aid in moving towards a more person-centred approach to care which focuses on building a caring and trusting relationship between residents and staff and supporting decisions that are based on the needs and preferences of everyone involved.

Conclusions

The widespread movement of culture change in LTC designed to provide person-centred care has received much attention from the research community, yet in most instances has ignored the voices of the residents who are at the centre of this care. Interviews with resident-participants living in facilities purporting to provide person-centred care revealed the extent of the participants' satisfaction with the care received.

They challenged the claims of person-centred care by describing the inadequacy of the caring environment, the human indignities, and the loss of personal autonomy experienced by themselves and other residents. In all, they posed serious challenges to administrative claims of person-centred care.

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