Care Providers are People Too!

Reassessing the Rhetoric and Practice of Person-Centered Dementia Care

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Abstract

Despite the current emphasis on relational care within dementia care literature and practice, long-term care centers continue to operate under a dominant reductionist logic which emphasizes “assembly-line” task completion and the individualization of care. This article explores the operationalization of Person-Centered Care (PPC) philosophy (Kitwood 1997) at two faith-based care centers in Alberta, Canada. While staff are versed in the PCC philosophy of care, and are often intent on delivering relational care, their efforts are often frustrated by systemic problems including chronic understaffing and lack of support by administration. It is argued that significant change needs to occur at the organizational and governmental levels of society in order to provide holistic care for persons with dementia, and that the concept of personhood needs to be extended to networks of care which also affirm the personhood of care providers and family members.

Keywords: dementia; person-centered; healthcare; neoliberal; long-term care; nursing

The concept of personhood is central to debates in the health sciences on topics of mental competency, human rights, and the beginning and end of life. However, biomedical approaches to conditions such as dementia often reduce the care recipient to a constellation of signs and symptoms. The approach of Person-Centered Care (PCC) is a direct challenge to this discourse and its dominance in the 20th and early 21st centuries. Cultural psychologist Tom Kitwood’s *Dementia Reconsidered* (1997) signaled a seismic shift in the philosophy of care, reconceptualizing the experience of dementia as psychosocial, based on a definition of personhood as a social status that we give to each other through our social interactions.

Kitwood’s book led to a plethora of academic studies and PCC-based dementia care programs, to the point where PCC has become ubiquitous, and equated with good practices of care.[1] However, his emphasis on the intersubjectivity of personhood is often lost in practice, as care recipients are instead treated as individual consumers of healthcare services, without sufficient attention to their relational context. This study suggests that the rhetoric of PCC is often used to serve a reductionist logic of care.

Furthermore, the care process is most often conceptualized as individualized and unidirectional, as personhood is considered only relevant to care recipients and not to family caregivers or formal care providers. A growing number of scholars are beginning to reclaim Kitwood's original vision of a more holistic, relational approach, which attends to the well-being of all involved in the care process (Adams and Gardiner 2005; Bartlett and O'Connor 2007; Dupuis, Kontos, Jonas-Simpson and Gray 2024; Kontos, Miller and Kontos 2017; Mitchell, Dupuis, Kontos, Jonas-Simpson and Gray 2020; Morhardt and Spira 2013).

Although several studies have argued that a holistic approach would necessarily support the spirituality of individuals with dementia (Toivonen, Charalambous, Subhonen 2018; Keenan and Kirwan 2018; Kevern 2015), little attention has been given to the intersection of faith-based care and person-centered care philosophy at Christian long-term care centers. At least one study has suggested that religion may in fact pose barriers to accessing dementia care (Regan, Bhattacharyya, Kevern, Rana 2013). Furthermore, PCC has also been critiqued by at least one Christian scholar, theologian John Swinton (2012), who argues that to be an embodied human being means to be in relationship with God. From this perspective, personhood cannot be diminished by a lack of social relationship. However, as Brett notes, "the philosophical point is well taken, but we may nevertheless continue to doubt whether this ontology will yield any significant differences in the practice of care" (Brett 2022:180).

With these concerns in mind, what is happening at Christian dementia care centers? What philosophies of care inform their approach to dementia? To what extent do they reflect viable alternatives to dominant models of care? Following the writing of Christian scholar Joshua Reichard, the task of sociology is to take a "healthy posture" of suspicion regarding the promises of care philosophies such as PCC (Reichard 2024), and to critically analyze how care interventions impact both care providers and recipients. In this article, I will explore the operationalization of care philosophies, their implications for care, as well as their strengths, limitations and challenges at two faith-based (Christian) long-term care centers in the province of Alberta, Canada. Through interviews and focus groups with front-line care providers, family caregivers, and care recipients with early-stage dementia, I argue that faith-based care centers are in many ways similar to mainstream care facilities in their reliance on PCC care philosophy. They also demonstrate many of the common concerns and critiques of PCC, particularly in

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[1] As Meranius et al. write, "The trend of advocating PCC as inherently good and as a quality goal to strive for is strong" (2020:1321).

relation to issues of understaffing, financial constraints, and a dominant reductionist discourse of care which reflects a broader neoliberal approach to healthcare, and which results in "epistemological violence" to those involved in the care process. In particular, I argue that care providers are caught in a perfect storm of conditions beyond their making, including chronic understaffing, time constraints, lack of support by management, and a reductionist logic of care at both governmental and organizational levels. While staff have the knowledge and capacity to deliver PCC, these conditions make it nearly impossible to do so. In conclusion, I will offer a few suggestions for change based on recommendations from care providers and family caregivers toward practices that are more holistic and life-giving for front-line care providers, as well as for families and persons living with dementia.

Personhood and Dementia Care

Kitwood writes that dementia forces us to reconsider life as inter-personal and inter-subjective: "identity remains intact, because others hold it in place" (Kitwood 1997:69). In contrast to care practices which often include elements of deception, treachery, disempowerment, and infantilization, and which are therefore "deeply damaging to personhood, possibly even undermining physical well-being" (1997:46), the aim of holistic care must be to "maintain personhood in the face of the failing of mental powers" (1997:20). PCC thus demands recognition of "the centrality of relationship, the uniqueness of persons, [and] the fact of our embodiment" (1997:7-8).

Kitwood's approach has been a watershed for discussion and writing on dementia care. While not the first to discuss the concept of a person-centered approach (see Parse 1995; Rogers 1951, 1959, 1961, 1986), his approach led to a proliferation of academic research and PCC applications. A recent search (February 20, 2025) on EBSCO using the terms "person-centered care" and "healthcare" returned over 17,000 articles and books published during the past decade. A similar search for "person-centered care" and "dementia" returned almost 4,000 articles and books during the same time period. Person-Centered Care has been referred to as "state of the art" care (McCormack et al. 2015), and has been identified by the World Health Organization as significant to the protection of human rights for vulnerable people (World Health Organization 2013).

Despite the renowned benefits of PCC, recent literature in the social sciences has begun to criticize this approach. While PCC is meant to be a holistic approach, the actual practice of care often reflects a dominant neoliberal discourse (Gottero 2021; Tieu et al. 2002) in its emphasis on ideals of autonomy and individuality, and on the management of bodies as a form of "biopower" (Foucault 2017). Individuals who have failed to achieve the ideals of autonomy and independence must be managed by the state, as exemplified within the field of healthcare and within the practice of dementia care. As Swinton writes,

> the capacities that are said to comprise personhood are always worked out by those in positions of power… behind these types of debates lies a particular view of what human beings are and should be and what desirable human living should look like…To be a person means that one must be able to live one's life, develop one's potential, and develop a purposeful life-course *without any necessary reference to others*. (2012:129-130).[2]

The model of the person implied in PCC philosophy also glosses over social identities and inequalities, failing to address diversity and difference within the field of healthcare and reproducing heteronormative assumptions of personhood (Foth and Leibing 2021). Smith et al. "understand the production of personhood implied in PCC as a white, colonial, cisheterosexual, able-bodied consumer" (2022:4).

Indeed, the rhetoric of PCC appears to have been co-opted by a dominant logic of care which emphasizes quantified health outcomes. As an example, one of the first assessments of PCC was Person-Centered Mapping, an approach which measures care in terms of minutes and numbers of care recipients served (Griffiths et al. 2021). Relational approaches to care "have a hard time surviving in an environment where reductionist assumptions shape how care is known, funded, organized and accessed" (Banerjee et al. 2015:29), and in which nurses, "whose knowledge and concerns were comparatively devalued as 'subjective,' are forced to make do and/or redefine their concepts of good care along administrative lines" (Banerjee et al. 2015:30). In the following discussion I will argue that, while faith-based organizations may define their purpose as different from mainstream care centers in terms of their theology, they are also significantly influenced by this dominant logic of care.

Theoretical Foundations

This article adopts a symbolic interactionist approach in its analysis of the creation of meaning within social contexts (in this case, long-term care facilities) through the shared symbolism of personhood (Blumer 1986; Mead 1934). Language is a key symbolic system, and terms like *person-centered* are promoted as fostering holistic well-being, particularly for vulnerable groups. From this perspective, specific care practices may be understood as symbolic exchanges, through which identity, values such as dignity and respect, and personhood are negotiated by participants in the care process. Yet person-centeredness has also been professionalized into a formal and individualizing model of care, eclipsing Kitwood's emphasis on relationality. Its ubiquity further implies that any organization practicing PCC must

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[2] "Remember that neoliberalism focuses on the individual – it values the person over the group or collective. People embracing the neoliberal ideology truly believe that ethics, morality and social ideals are the responsibility of each individual person, not the state and certainly not private enterprise" (McGregor 2001:85).

automatically be a good care provider. As Dorothy Smith (1990) argues, language does more than describe reality; it organizes social life through ‘relations of ruling’ that marginalize certain voices. In this context, *person-centered* discourse can shape power relations in care, reducing the process of care to a series of discrete tasks, and subordinating care providers to the status of non-persons by failing to recognize them as unique individuals and to provide them with holistic affirmation and support.

Methodology

This article takes a qualitative case study approach (VanWynsberghe and Khan 2007) to the philosophy and practice of dementia care within two faith-based (Christian) long-term care centers. Qualitative case studies provide an in-depth exploration of a topic within real-world and bounded contexts (Hyett and Dickson-Swift 2014), in this case allowing for a critical assessment of the philosophy, delivery, and impact of care within two healthcare settings. In 2022, my research assistant and I sent letters of invitation to 90 faith-based (Christian) long-term care centers across Canada, requesting their participation in our research. We also conducted on-line research to identify the care models implemented at each of these locations. While five care centers expressed initial interest, two care centers located in the province of Alberta ultimately committed to participation in the study. The low rate of participation was undoubtedly influenced by the COVID-19 pandemic. In total, we conducted eight on-line focus groups and interviews through Zoom with a total of 50 front-line care staff, 3 family caregivers, and 9 individuals with early-stage dementia. The category of front-line staff included health-care aides, registered nurses, recreation therapists, therapeutic assistants and an occupational therapist. Focus groups with early-stage dementia included a support staff in case participants became distressed. Participants were recruited through announcements and posters at dementia care centers, and responded directly to the principal investigator of this study to indicate their interest in participating. Their identities were protected through informed consent forms, which required confidentiality by all participants in focus groups and interviews, including support staff in focus groups for residents with early-stage dementia. This study was funded by a Vandezande Restoring Hope Grant, provided through Redeemer University. Focus group and interview questions included the following:

- How would you describe the care you provide/receive (or that your loved one receives)?
- Are you familiar with ‘Person-Centered Care’? What does this phrase mean to you?
- Please describe what PCC means for the care you provide/receive.
- What values inform the care that you provide/receive?
- What is important to you about the care that you provide/receive?
- What are some challenges to providing care?
- What changes would you make to the care at your care center?

Focus group results were then analyzed for dominant themes regarding the operationalization of PCC, its strengths, and the barriers to its practice. The study received ethics approval from the Research Ethics Board at Redeemer University (REB #2021-01-10), the Covenant Health Research Centre (#Pro00122114), and from each of the participating long-term care centers.

Data Analysis

This study adopts the Creswelland & Poth Data Analysis Spiral (2018) in its five-step approach: data management and organization (organizing the raw data of focus group and interview transcripts), reading and memoing (identifying emerging ideas and concepts), describing and classifying (developing codes which were then grouped into broader themes), developing and assessing interpretations (developing deeper interpretations of themes, reflecting critically on findings), and finally representing the research data in the form of this article. Focus group data were coded and organized into themes of care values, care practices, and barriers to care.

Limitations

Case studies such as this are limited in terms of their applicability to other contexts and situations. Owing to the study's restricted scope and modest sample size, the findings are not generalizable beyond its participants. Nevertheless, it may have limited transferability to analogous contexts.

Person-Centered Care

Since the publication of *Dementia Reconsidered*, PCC has become the dominant model of dementia care in North America and Western Europe. Mary Godfrey et al. report that "Person-centered care has become ubiquitous in UK health and social care policy discourse as synonymous with care quality" (2018:2). While several other models of care enjoy some popularity, most notably The Eden Alternative and its Greenhouse Project (Tavormina 1999), this study found that PCC was also the most common philosophy of care in Canadian faith-based long-term care settings. Front-line staff consistently referred to PCC as the philosophy of their care center, although at times referring to the approach as patient- or client-centered.

However, the terminology of PCC is almost exclusively used by administration and front-line care providers, as only one of the family caregivers and none of the individuals with early-stage dementia were familiar with this term. One family member guessed at the meaning of PCC: "I think it means that you center on each individual and their needs and try to meet their needs as best you can." However, she did not recall ever hearing the term at her loved one's care center. Another said, "I feel like I read something on the website. I can't recall what it is, and I don’t feel there’s been a pattern re-enforced to me.”

Furthermore, PCC refers to a unidirectional process of care, directed toward individual care recipients whose personhood is at stake. In this way, PCC is symbolic of a hierarchy of care which often ignores the agency of care recipients and denies the personhood of care providers.

For staff who participated in this study, the rhetoric of PCC was ubiquitous, informing the training and daily work of nurses, therapists, and other staff. For example, one reported that “My entire four years of nursing school was based around PCC. I came into nursing with that experience in mind, and it’s been in the back of my mind ever since.” Staff received regular training and reminders of this approach to care in the form of monthly and annual meetings, communication between Directors of Care and staff, and posters in elevators, all of which symbolized the hierarchy of care. Staff were also evaluated in terms of the level of person-centeredness in their care practices. One recounted that “the verbiage is used quite frequently, especially whenever they’re talking to the team…Our coordinator writes up examples of excellence in PCC.”

However, the rhetoric of PCC and the emphasis on care providers as responsible for the delivery of relational care chronically disregards systemic barriers to its implementation, which in turn reflect a broader sociopolitical ideology emphasizing individual responsibility and accountability (Sinno et al. 2024). The continued usage of PCC terminology also reflects Neil Stammers’ (2009) “paradox of institutionalization” in which a concept originally meant to challenge systems of power (such as personhood or human rights), when institutionalized into formal rules and procedures, begins to support those same power structures. This is exemplified by front-line staff who said that the introduction of PCC as a formal care philosophy actually frustrated their practice of relational care. As one lamented, “we’ve been doing PCC all along… but since it’s become formal, we have more paperwork!”[3]

Several participants mentioned that adopting the approach of PCC put their care organizations on the map as part of the care center’s marketing strategy. One reported that “I’ve been with [long-term care center] for 20 years now… We’ve been doing this all along, but the term became popular 12 years ago. Now there’s more attention to it.” Another speculated that “That’s how they sell what they’re about, and their expectations.” However, these marketing strategies did little to deliver any tangible support for front-line care providers themselves.

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[3] “Regulations intended to provide accountability often mean that RNs are responsible for more paperwork than care work and that there is a hierarchical division of labour” (Lowndes and Daly 2017:42).

PCC Values and Practice

Staff, care recipients, and family members identified specific values as central to the practice of good care. Staff were unanimous and consistent in identifying the core values of PCC: dignity, respect, and resident choice. In addition, the following were mentioned in focus groups and interviews: empathy, compassion, patience, love, creating a sense of home for/with the residents, spirituality, affection, privacy, confidentiality, accountability, stewardship, quality care, and accommodations for the resident. Several respondents identified these values as corresponding to the Christian values of the care organization, and to their own personal values.

> [#1] What are our values? Religion is important at [care center]: culture, dignity, faith, accountability, and stewardship… [#2] When you look at their values, the values that surrounds [care center], a part of it is their faith base, along with person-centered care… Faith becomes the center. That puts [care center] on the map because of its values.

Values were often paired together in their responses: for example, respect and choice; dignity and privacy. In addition to more philosophic rationales, staff sometimes had very practical reasons for applying these values to their care, such as the reduction of aggressive behavior. Specific care practices also serve as symbolic markers—"identity pegs" (Goffman 1968)—which re-enforce the status of personhood in care recipients. Staff often mentioned respect in terms of resident identity, such as showing respect for the care recipient's background, including culture, ethnicity, spirituality, likes/dislikes, as well as decision-making autonomy, such as making decisions regarding times for going to bed and rising in the morning.[4] For example, "Some people want to go to the church service, others don't want to join. We respect their choice." Dignity was discussed in terms of resident privacy in the process of receiving personal care, including bathing and dressing, and was closely related to the concept of respect. As one respondent summarized, "Listen carefully; you don't need to rush them. Listen attentively and carefully to what they want. Cultivate the dignity of the patient."

Staff also identified values of compassion, patience, and accountability as central to relational care:

> [#1] If you don't rush them, then their behavior is fine, they agree with whatever you tell them to do. They say "thank you for giving me good care."… [#2] If they're having a bad day, a resident is crying, give them a hug, take them for a

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[4] On choice, see Armstrong and Daly, 2017.

> walk around the unit if they're mobile, spend one-on-one time with them…. [#3] If I know someone's sick, then it's my responsibility to check on them.

Staff acknowledged the importance of using "people-first" language (for example, "resident with dementia" instead of "dementia resident"), and being attentive to the cultural background, religious affiliation, and habits of each care recipient. They also generally agreed on the importance of using the personal names of care recipients when interacting with them. This was appreciated by residents, as reflected by the comments of two care recipients:

> "[#1] They call me [by name]. They don't call me a client or resident... [#2] My name is on my door. People know my name, so that's good."

One focus group participant said that PCC involves "getting down to [the care recipient's] level" in terms of communication and the practice of care (for example: making eye contact, sitting down when the care recipient is in a wheelchair). Staff also described PCC as affirming the care recipient's independence to the extent possible, while ensuring their safety. Perhaps most significantly, staff said that PCC means knowing the care recipient personally—their life situation and needs—and listening to them.

Care recipients also mentioned specific values as central to the care that they received, which mirror the list mentioned by staff: love, affection, home, choice, respect, and dignity. When asked to describe the care they were receiving, care recipients focused on tangible and practical aspects, including help with daily tasks of dressing, hygiene, and taking medication:

> [#1] I like this place. It's good, I've got my computer and a TV… [#2] The staff treat me well; if something's wrong they tell us… [#3] Staff are very accommodating; they help you day by day by day.

While care recipients did not recognize the phrase "person-centered care," they did identify aspects of care that they felt were most important, ranging from the practicalities of assistance with daily tasks to a sense of being at home. Their responses often emphasized practical, tangible aspects of care.

> [#1] I get fed every day: breakfast, lunch, dinner…The food is excellent… [#2] When I had my pacemaker and I was weak, people supported me.

Care recipients also emphasized their own happiness and that of others as important ("I meet people here; they're happy, they're enjoying themselves. That tells you something."), and expressed a strong sense of appreciation for care staff and their approach to care, including support for their spirituality:

> [#1] One thing I really enjoy is the people that are here now. They do a heck of a good job…. [#2] Staff clearly explain things…We are called by our names… [#3]

> Faith is important to me… I feel at home here, because I can pray…We pray for everybody.

Although family caregivers agreed that values of respect, dignity and choice should be at the forefront of PCC, they also shared concerns that these values were not being realized in the care that their loved one was receiving. They described the care as “perfunctory, rule-adherent, and routine,” and as reflecting “a generic set of values.” Although family members were concerned about the availability of staff (“you can’t find a nurse anywhere”), they tended to place responsibility and blame on the organization rather than on staff.

> [#1] The staff is doing their very best; it’s not the staff’s fault, it’s the organization that doesn’t hire more people… [#2] There have been a few individuals who have really seen my [family member] as a person, but that doesn’t feel like it’s part of the policy that’s governing what’s going on.

Family members were also concerned about the physical condition of the care center, including an elevator which had been out of service for a month (“how can that be a value of safety?”), the level of care their loved one was receiving (“one of the nurses that was on there said this isn’t 24-hour care; if you want 24-hour care, you need to pay for it”), and the general understaffing of the care center.

> It seems to me that when this organization was started, it was a faith-based organization run by the church or whatever and they were very, very focused on bringing quality of life and everything, but since the government took over that has kind of been pushed away and they are so understaffed that they cannot do person care or whatever you call it because there isn’t enough staff to look after that.

Finally, family members were concerned about support for their parents’ spirituality. One family care recipient said that faith was being “weaponized” against their parents, who had been prevented from hugging at the end of a meeting.

> We could get down to the medication list, but we can’t talk about that she wants to give my dad a hug at the end of a meeting when she has Alzheimer’s Disease in the middle of a pandemic… for heaven’s sake, this is supposed to be a safe Christian environment where people can be recognized as humans and their relationship with a higher power.

Faith appeared to be particularly important for several family caregivers, who associated a personal evangelical faith with PCC philosophy, and who were concerned by what they perceived as a movement away from faith-based relational care:

> It feels very institutionalized; that's not how it was in prior years because I've had family here before… the care was totally different. It was faith-based and person-centered, like a church family. Everybody knew each other, but now you're a number or you're occupying space, and you just don't have any personal connection.
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> My husband I are of an evangelical faith, very personable and very real to our lives. I appreciated your prayer; but I don't see that in the facility, not when I'm there. They said at the meeting that I went to before, something about not all the staff shares Christian values. So it would be nice if somebody when they're putting him to bed at night, could stop and have a little prayer with him, but I don't know if you can expect that, or read the Bible to him. Perhaps that's above and beyond the call of duty.

Reciprocity

While not listed as a central value of PCC, staff emphasized the importance of reciprocity in their care practice, and in doing so challenged common assumptions of care as a strictly unilineal process. Within academic literature, the categories of 'care provider' and 'care recipient' are most often assumed to be mutually exclusive. Janice Graham and Raewyn Bassett note that

> for the majority of researchers asking the person with Alzheimer's disease about themselves and their relationships with their caregivers, a relatively fixed relationship between caregiver and the person with Alzheimer's disease remains implicit, foregoing investigation of the range and complexity of relationship experienced (2006:336)

However, more recent studies have identified the role of people living with early-stage dementia as active co-producers of care (Bosco et al. 2019), and the importance of reciprocity in care for the well-being of both the care provider and care recipient (Dobbyn 2024; Graham and Bassett 2018). Several recent studies have also identified the importance of recognizing and affirming the personhood of care providers, which is often neglected in the practice of PCC. Some studies have argued that persons living with dementia can reciprocate care, at least in the early stages of their disease (Dobbyn 2024).

The comments of front-line staff reflected a sense of reciprocity, as both care provider and care recipient come to know one another and build a sense of trust, especially in terms of listening to the care recipient or giving them voice. "They're given the quality of care, considering their voice, their own decision, even though they're not entirely alert." Staff felt that good care necessitated a relationship with the care recipient, in which the care provider knew of the person's background, character, and preferences.

> When you go to work, you know the person you care for, and you know exactly who they are. If there's something wrong you can notify the team leader, and you go home and feel good that you did something good for your resident.

Staff also emphasized the importance of care networks and teams, including other staff and family members, and the centrality of clear communication, mutual respect, and trust in the formation and maintenance of these networks: "that's the only way the residents feel it's consistent and safe. If everybody is doing something different, they get confused." Another care provider said:

> It's not only me working here; when someone's sick it's not only me who knows it. If I know someone's sick then it's my responsibility to check on them. You do your assessments, it's like a chain of communication from one staff to another. Then it goes to the RN, then there's a team involved.

Empathic understanding was also important to staff, who imagined themselves, or their loved ones, in the situation of care recipients, and were motivated to provide the quality of care that they would like to experience themselves: "I treat everybody like I want to be treated." However, staff also emphasized their roles as care providers delivering individualized care, suggesting some tension between the holistic ideals of PCC and the actual practice of care.[5] Care providers are located in the tension between the local care setting, the ideals of PCC, and the broader neoliberal discourse of individualism in its emphasis on "the personal accumulation of skills and the devolution of responsibility to the individual" (Mead 2021:24). This tension often results in care providers understanding the principles of PCC and trying to implement them in practice, but being frustrated by the reductionist logic of individualized care and the restrictions of the care setting (especially staff-resident ratios), and by the feeling of being denied their own sense of personhood.

> It's easy to become task-focused, you have a certain amount of time and stuff to do. There are real challenges in providing the amount of care that you would want to, or taking the time with that resident that you would want to.

PCC Care and Violence

Despite the current emphasis on relational care, long-term care facilities often commit "epistemological violence" (Banerjee et al. 2015) against care providers, family caregivers and

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[5] See (Armstrong 2017). According to Kontos et al., the central limitation of PCC is "the decontextualizing of the individual from relationships with others (2017:183).

care recipients by reducing “complex relationships of care…to a series of tasks, which challenges care workers’ self-worth and self-efficacy and negatively affects the delivery of PCC” (Meranius et al. 2020:1325). In doing so, administration at care facilities presents institutional policy as holistic and truthful while disregarding the lived experiences of both care providers and recipients. Staff are expected to deliver relational care while completing an exhausting list of tasks, which ironically are compounded by systemic barriers to PCC. When asked to identify challenges to the provision of PCC, staff were quick to respond with a lengthy list of concerns, centering around understaffing, lack of time, lack of support by management, and the increased complexity of resident behavior and needs.

Understaffing

Front-line staff and family caregivers agree on one thing: understaffing compromises PCC by reducing the amount of time that staff can provide to each resident and at the same time increasing the workload for staff. For staff, this often resulted in work overload and burnout, and a lack of time to provide relational care.

> There’s not enough manpower. In assisted living we do everything; we scoop the food, we bring them in, we do the dishes, shower, cleaning, laundry and then we have short staff. And then, from 1:30, there’s only two full time staff left, who when everybody needs help, there are not enough hands to help with the residents. We discussed this with management, we had a meeting, but they say that’s the only staff ratio they can do for us.

Family caregivers were generally in agreement that insufficient staffing posed a barrier to relational care, and that COVID only exacerbated these conditions. Residents were locked in their rooms to prevent them from wandering, and family members arrived for visits to find their loved ones with full diapers from the previous night.

> [#1] It feels like so often if somebody is quiet in their room, they’re not needing the care that somebody who is louder or more vocally in need is getting from the very limited number of people who are there… [#2] They say “just sleep through the night, don’t bother getting up to go to the bathroom. It disrupts. They said just do it in bed.” I think in a way it makes you feel degraded; if you have any self-respect you go to the bathroom

Time

Understaffing was consistently coupled with a lack of time to practice relational care. Care providers struggled to meet the needs of up to twenty residents within their shifts, which resulted in an increased emphasis on task-completion rather than relationship building. One care provider said “I wish there were five of me. I want to read them a book, but I don’t have time and I need to take care of myself too." Staffing shortages also meant increased workloads for health care aides, who took on duties and responsibilities beyond their job description.

> [#1] We have to wash dishes and prepare food; that's taking time from us to spend with residents. The family expects that we will spend time with residents. Instead, we're doing paperwork, laundry, cleaning their room if someone is incontinent, making a mess. It's very hard. Our break never happens, maybe 15 minutes; put information into the computer, we rush drinking and eating. There is no way that we can finish what we need to… [#2] We have to go through security at 9:00pm and check the building. I wish that could be taken away, and washing wheelchairs because that's cutting from resident care.

Staff reported feeling 'rushed,' resulting in agitation for both care provider and care recipient:

> Does PCC really work when you have to care for ten residents on an eight-hour shift, serving 2 meals, cleaning their rooms, and doing their laundry? ... there's no time for talking, singing, cracking jokes, just to let them feel like they're home away from home, that this is their home now.

Resident Characteristics and Behavior

Shortages of staffing and time were compounded by concerns about the changing needs of care recipients. Several staff reported that residents were being admitted with increasingly complex and high-level needs including advanced dementia, and associated these changes with government policy which encouraged "aging in place," but which failed to account for the impact on care centers and their staff[6] when care recipients were admitted with advanced levels of dementia, including aggressive behavior and wandering. As one care provider said, "if someone's aggressive… it's hard to do PCC." Staff reported needing extra hands to address the increased tendencies of care recipients to wander, and found it more difficult to take their needed breaks. Care centers faced increased challenges for those residents whose dementia was advancing, but who remained in assisted living units due to dementia care units being full.

> Our residents are much 'heavier.' We used to have residents that were still going to the mall, driving their cars. You'd go in to help them put their stockings on and they'd do the rest themselves. So the staff had more time to make that care person-centered or to build that relationship with the resident. Whereas now the residents need a lot more care, they're having a lot more behaviors, more physical challenges.

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[6] For a critique of 'aging in place,' see Armstrong and Daly, eds. 2017.

> I think they're sending people here with more complex issues. It's just not easy to care for them with the amount of staff we have. That creates problems everyday…I'm pretty sure they qualify people differently… It doesn't feel like home anymore, it feels like a hospital. That requires more staff, and we have less staff.

Another family member expressed a similar perspective:

> The government has said they want people to stay in their homes longer, put in home support, so those families get used to having one on one there… so people are staying in their homes longer. People in condos here are not going into long-term care until they've fallen. Ten, fifteen, twenty years ago, people were going into long-term care in their 80s and staying there for 15 years. The government put a lot of money into keeping people in their homes, but didn't focus on long term care. The money goes to at-home services, but you can't keep everybody at home, due to certain conditions and disease. There are lots of criteria; not everyone can stay at home, it's not feasible. People will come to long-term care. We need to be more realistic about the people who are in long-term care.

Lack of Support for Staff

The emphasis on individualized care often obscures the need for all participants in the caring process to be well and to feel valued. Institutional policies which fail to acknowledge and affirm the lived reality and needs of care providers are symbolic markers of their status as non-persons. As an example, staff expressed considerable frustration over not being understood or supported by management:

> If we have a problem, there's no management coming up to help us, because they think that we're equipped and we know exactly what we're doing, but we still need people there, we still need the management with us. They're just leaving us. We can't just deal with the resident without them taking care of us. We need support from them.

Staff felt that they were being underpaid, and identified this as evidence of being devalued by administration: "Many staff are part-time. If they were paid more per hour and people work full-time, then we can give quality care." One family member echoed this concern: "They're not really paying these nurses or care workers a great wage."

Risk

In her discussion on meaningful choice in long-term care, sociologist Pat Armstrong argues that while it is important to avoid unnecessary risk, an overemphasis on risk prevention may pose significant obstacles to care providers and care recipients, and to the practice of relational care. In her words, "When medical services are what count the most, then many of the activities that make life worth living are eliminated. It becomes more important to take the pills than to enjoy the meals, and time pressures often mean one must be sacrificed for the other." (Armstrong 2017:122). Staff were clear in their comments on the challenge of balancing relational care and individual choice with resident safety.

> There's a person that couldn't eat bread or couldn't eat certain things because of a choking risk. That particular person could sign that waiver and did, that they eat it anyways and they're good with that. Some don't have the capacity to do that, so decisions are made for them. We can't let them lie in bed because they'll fall out. It's tough when you want to give PCC, but they're not their own spokesperson.

Individual Choice and Congregate Living

Staff found it challenging to support individual preferences within a care environment with multiple resident demands and insufficient staffing.

> It's very easy for us to offer choice: "What do you want to wear today?" But when someone is demanding extra attention that takes away from other residents, that becomes a bit of a problem, and that could be an expectation of families that we spend extra time with them when in reality we may not be able to.

Communication

Staff expressed some frustration with the lack of clear and efficient communication between care providers and care recipients, and between members of the care team. Poor communication resulted in confusion for both providers and recipients of care.

> We need to understand and respect each other in making decisions, because sometimes we don't listen to each other…Communication is very important; that's the only way the residents feel it's consistent and safe.

Physical Environment

Staff expressed concern with the aging physical environment of their care setting, including broken ceiling lifts and the size of room air conditioning and lighting, all of which impact the care process:

> In Occupational Therapy, we have challenges with the physical environment, doing mobility things and transfers. This place was built in the 1960s, and there are limitations because the toilet is too close to the wall. There are other

> challenges with the physical structure: the size of the room, the shape of a room, its dimensions, air conditioning, heating, if it's too hot in the summer with no AC and too cold in the winter, power outages, back-up generators, lights, pipes bursting which lead to floods and then you cancel your shower or wash in cold water. Sometimes staff have to wash their hands fifty times a day in cold water. You can't do the "creature comforts."

Family Expectations

Staff experienced frustration with what they perceived as a lack of understanding by family caregivers. Care providers felt that family members were unrealistic and demanding in their expectations of the type and level of care their loved one should receive.

> Sometimes the person can't be left alone; then what are you going to do? The family says she can't be left alone: "I'm going to sue you if she falls; I'm going to do this, I'm going to do that", and that's not realistic. The staff can only do so much. We all want more staff, but it all comes down to families needing more education on what their specific loved one's dementia might look like in the future, and what can be expected, and I think that would really take a lot of the burden off what they feel as a family. It's so hard for them. Some families are really realistic, but some families don't seem to get it. We refer them to the Alzheimer's Society, but the Alzheimer's Society isn't really hands-on. That's part of the problem.

Proposals for Change

We asked respondents if they had any suggestions for change to their care practice, or to the organization. Front-line staff and family caregivers agreed that the most important change would be to hire additional staff who were trained in PCC. This would allow each staff person to provide more time with each resident, reducing safety risks for both staff and residents, as well as overwork and exhaustion for staff. One respondent identified a need for volunteers to supplement staff. Respondents realized that this would require more funding, and identified a need for change at the level of the current government. As one staff member suggested,

> Give us more time to spend with the residents, to know the residents, just sitting with them because when you understand them you can give them that quality of care that they need. We need more staff, especially for the evening time. We feed people, put them back to bed, but there's no time to just talk to them, to know them better.

Family caregivers also identified the need for additional staffing*:* “The staff is doing their very best. It’s not the staff’s fault. It’s the organization that doesn’t hire more people.”

Staff also expressed a need for additional support from management, and a greater role in decision-making together with management. Staff felt that critical decisions were being made by people who did not understand the challenges of front-line care providers:

> [#1] They don’t care for us or the residents, but they want business. HR makes all the decisions, which is in my opinion not right… [#2] Take good care of staff, learn to listen to staff. Policies are made by people in the offices, they don’t know how the unit works. It looks good on paper, but try to do it practically on the unit, and doesn’t work. We have to change that, how healthcare works before you start sitting at the desk making all those changes, and then they want us to do that. It’s impossible.

The lack of support from management impacted morale among care providers. Instead of hiring more staff, management made staff “work short,” meaning that care providers had to perform duties outside of their job descriptions. Working short also meant that staff were under pressure to forego their work breaks, increasing their stress levels and relegating them to the status of non-persons by failing to recognize their needs.

> PCC is only for the residents. In reality, we are not just working with the residents, we are cleaning the room, we are kind of housekeepers; we are washing the dishes, so I don’t know: where is this PCC really? It’s not for staff, it’s just about putting the organization on the map. There’s no PCC for us, it’s about the residents and their families.

> It’s not healthy for the staff; we’re always overwhelmed. We’re always overstretching our bodies. Of course, if you’re not healthy anymore, how can you provide quality care for the residents? We’re frustrated because you don’t have time to talk to them; how will you know the resident, except that as I said a while ago you are doing the interview and everything, we are posting it to their room. Sometimes the staff are not reading that anymore because we don’t have time, because we’re always understaffed. We don’t blame the organization… it’s just because of the budget of the government.

Staff also identified the importance of strengthening relationships with families, especially in the form of educating families in terms of their loved one’s needs and care situation (“Families want perfect lives for their parents. We can’t provide that.”). This would ideally result in more realistic expectations by families, and greater involvement of families in care: "They need to learn what that is and looks like and how they can contribute in a positive way. Otherwise, our time is wasted."

> It's frustrating to watch a health-care aide being berated by a family member. That person is supporting your loved one, and you're taking time away from that by yelling at them. If I went into your home and threw your stuff everywhere, that would be wrong. Bring the family members into the fold. The next step up from PCC is not to just focus on the person but the family-centered care needs to be there.

Family caregivers also expressed a need for additional programming such as interaction with nature, music, exercise, and history talks, as well as spiritual care:

> It would be nice if somebody when they're putting him to bed at night, could stop and have a little prayer with him. But I don't know if you can expect that, or read the Bible to him. Perhaps that's above and beyond the call of duty.

Finally, care providers identified barriers to relational care at the level of the Alberta provincial government, which they identified as downloading responsibility for senior care to families and individuals,[7] emphasizing healthcare as the individual's personal responsibility (Anderson 2020). Staff also connected the understaffing of their long-term care facilities and the growing complexity of resident needs with the reduction of long-term beds, a change driven by government policy.[8]

> We used to have more dementia and long-term care centers. Those places closed down or the government shut them down. Regular long-term care is not regular long-term care; it's long-term care mixed with dementia mixed with psychiatric care. But the staffing ratios are based on regular long-term care. Residents are completely different than they used to be. That doesn't reflect the type of residents we need to look after. It drastically affects us in terms of safety for residents and ourselves, and a lot of other things. How is that going to change in Alberta with the government we have or in Ontario with the government [they] have? COVID was supposed to shine a light on long-term care. It shone a light; where are the studies that came out, all of these recommendations? One of the recommendations was that everyone should have a private room. How is that going to happen? Are they going to bulldoze all of these buildings, renovate the building? Where are the residents going to go in the meantime? It's not

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[7] The province of Alberta was featured in national Canadian news during COVID due to its emphasis on personal responsibility for healthcare during the pandemic (CBC 2020).

[8] Long-term care beds were reduced per capita in Alberta by over 40% since the 1990s (Armstrong, Armstrong, and Choiniere 2015:7).

> realistic; they don't come up with solutions that are real. There are a lot of places in the world that have come up with solutions that are fantastic. PCC is of course at the crux of a lot of them, but there are way more ideas if people just opened their eyes to possibilities. The whole system could be drastically changed, and everything would be so much better, but instead we're stuck in these little molds that our government puts us in.

Conclusions

Front-line staff at these care centers are knowledgeable about, and committed to, the values of PCC. They can readily list the values of PCC and provide examples of how they implement PCC in their daily care-related tasks. However, their efforts are frustrated by the organizational and sociopolitical contexts of their care practices, which make the delivery of relational care nearly impossible. Most significantly, staff expressed frustration with current staffing levels and resultant time pressures, the growing complexity of care recipient behavior and needs, and administration's neglect for the well-being of front-line care providers. While staff identify the care organization as responsible for levels of staffing, they also acknowledge that the organization operates within the broader context of the system of healthcare and long-term care within the province of Alberta, and that change needs to occur at both organizational and political levels. Finally, staff expressed frustration at the lack of support they perceived as coming from management. As one care provider exclaimed, "Is PCC only for residents? We're not treated as people!"

These concerns were often supported by comments from family members who were frustrated by the lack of care they felt their loved ones were receiving, but who also recognized that staff were subject to pressures from their workplace and the broader sociopolitical context of care. Care providers are indeed situated in the tensions between the ideals of relational care and a healthcare system which has co-opted PCC rhetoric, but which continues to rely on a dominant logic of care emphasizing individualism and personal rather than collective responsibility. The limits of PCC as currently operationalized point to the need for integrated healthcare networks in which persons with dementia, care providers, and family caregivers are all recognized as interdependent and valued as persons. Recent literature on relational care has begun to address these concerns, but this study suggests that much remains to be done at the level of front-line care provision.

Faith-based care centers are key places to model philosophies of care which include and affirm all participants in the caring process. Christians must be thoughtful and creative in developing care networks which promote the inherent value and dignity of care recipients, care providers, and family members.

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