

“I Hope That the People Caring for Me Know About Me”: Exploring Person-Centred Care and the Quality of Dementia Care



Bryan B Franco, MD¹, Veronique M. Boscart, RN, MSCN, MED, PhD², Jacobi Elliott, PhD³, Sherry Dupuis, PhD⁴, Lisa Loiselle, MA⁵, Linda Lee, MD, CCFP(COE), FCFP, MCISC(FM)^{6,7}, George A. Heckman, MD, FRCP(C)^{3,8}

¹Department of Medicine, University of Alberta, Edmonton, AB; ²CIHR/Schlegel Industrial Research Chair for Colleges in Seniors Care, Conestoga College, Kitchener, ON; ³School of Public Health and Health Systems, University of Waterloo, Waterloo, ON; ⁴Partnerships in Dementia Care Alliance and Department of Recreation and Leisure Studies, University of Waterloo, Waterloo, ON; ⁵University of Waterloo, Waterloo, ON; ⁶Schlegel Research Chair in Primary Care for Elders, Conestoga College, Kitchener, ON; ⁷Department of Family Medicine, McMaster University, Hamilton, ON; ⁸Schlegel-UW Research Institute for Aging, Waterloo, ON

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ABSTRACT

Background

Person-centred care is at the core of high-quality dementia care but people living with dementia are often excluded from quality improvement efforts. We sought to explore person-centred care and quality of care from the perspectives of persons living with dementia in the community and their care partners.

Methods

We used a qualitative descriptive approach with in-person, semi-structured interviews with 17 participants (9 persons living with dementia and 8 care partners) from Ontario, Canada.

Results

Participants report that person-centred care is essential to the quality of dementia care. Three themes were identified that describe connections between person-centred care and quality of care: 1) “I hope that the people looking after me know about me”, 2) “I just like to understand [what’s happening] as we go down the road”, and 3) “But the doctor doesn’t even know all the resources that are available.” Participants perceived that quality indicators over-emphasized technical/medical aspects of care and do not entirely capture quality of care.

Conclusions

Persons living with dementia and their care partners provide important insights into person-centredness and quality of care. Their perspectives on “quality” may differ from clinicians and researchers. Research is needed to better integrate their perspectives in quality improvement and person-centred care.

Key words: person-centred care, dementia, quality of care, quality improvement

INTRODUCTION

Ensuring the quality of care for persons with chronic illnesses has emerged as a leading global priority.⁽¹⁾ However, those living with Alzheimer’s disease and related dementias face unique challenges often associated with suboptimal care compared to those living with chronic diseases like diabetes.^(2,3) In recognizing and aiming to address these challenges, contemporary practice has embraced person-centred care enthusiastically such that it has almost become synonymous with the concept of high-quality dementia care⁽⁴⁻⁶⁾ despite often unclear definitions,⁽⁷⁾ barriers to operationalization,⁽⁸⁾ and limited evidence of successful implementation in quality of care frameworks.

Given the many definitions of person-centred care, there is consensus that it generally involves appreciation of people’s subjective experience of illness and recognition that care should focus on the person and not the disease.⁽⁹⁾ The late Tom Kitwood’s definition is arguably the most recognized and established articulation of person-centred care with regard to dementia. Kitwood’s definition consists of four components: valuing persons living with dementia and their care partners; treating them as individuals; looking at the world from their perspectives; and providing a positive social environment for them to experience wellbeing.⁽⁴⁾ Despite its popularity, the operationalizability of person-centred care remains limited. For example, Dementia Care Mapping, which is underpinned by Kitwood’s definition, is the only dementia-specific tool for

measuring person-centred care, but is limited by its design for use in long-term care and inpatient settings⁽⁹⁾ and its reliance on others to assess quality for persons living with dementia.⁽¹⁰⁾

The experiences of people living with dementia and their care partners are essential to understanding person-centred care,⁽¹¹⁾ and, consequently, the quality of dementia care. Some studies have explored potential components of person-centred care by engaging persons living with dementia and their care partners.⁽³⁾ These studies include investigating concepts such as satisfaction with⁽¹²⁾—and perspectives of—quality of care,⁽¹³⁻¹⁶⁾ suggesting that persons living with dementia can meaningfully contribute to understandings of person-centred and high-quality care. However, there is a dearth of literature exploring both person-centred care and quality of care,⁽¹⁷⁾ which precludes making explicit connections between these two important concepts and their integration into quality improvement efforts.

This gap in evidence may be a consequence of excluding people living with dementia from research.^(17,18) In their 2013 systematic review, Prorok and colleagues⁽³⁾ found that less than half (21 of 46) of identified qualitative studies included people living with dementia. This trend appears more pronounced in quality assurance and improvement research, with separate 2020 and 2013 systematic reviews failing to find examples of any patient involvement in quality indicator development for dementia care.^(19,20) Hence, despite the recognized inextricability of person-centred care and the quality of dementia care, there is a lack of understanding about the connections between the two concepts.

This manuscript presents the findings of a qualitative study exploring person-centred care within the context of quality care from the perspectives of persons living with dementia and their care partners in the community. Specifically, we explored the perspectives of people living with dementia and their care partners on: 1) the definition of person-centred care; 2) how person-centred care impacts quality of care; and 3) quality indicators for dementia care that were developed by clinicians.⁽²¹⁾

METHODS

Qualitative approaches to research have shown promise in involving persons living with dementia, particularly in relation to evaluating quality of care.⁽¹⁷⁾ We used a qualitative descriptive method, including content analysis, to explore the perspectives of people living with dementia and their care partners on person-centredness and quality of dementia care. This approach is consistent with our emphasis on understanding the perspectives of individuals living with dementia and their care partners. It allows us to describe participants' perspectives by immersion in the data (i.e., without the use of an a priori theory or much inference in analysis).⁽²²⁾ The authors conducted semi-structured interviews with persons living with dementia and their care partners between October 2016 and July 2017. Care partners included the main informal caregiver (usually a family member) for the person living with

dementia. The University of Waterloo's Office of Research Ethics approved this study (ORE# 21501) and all participants provided informed written consent.

Setting and Participants

Participants were recruited from two local Alzheimer Society programs and one primary care memory clinic in an urban setting in Ontario, Canada. We used both passive and active recruitment strategies, such as flyers and brief presentations during Alzheimer Society gatherings. To solicit diverse perspectives, we sought to recruit persons living with mild-to-moderate dementia who received care from primary care-based memory clinics or specialists. To ensure the recruitment of participants who were able to participate in an interview, we limited active recruitment to individuals who were still able to respond verbally to questions, which served as a proxy for mild-to-moderate dementia. The Functional Assessment Questionnaire, a measure of independence that correlates with cognitive status and helps distinguish mild cognitive impairment from mild dementia, was administered to each participant.⁽²³⁾ If available, participants' care partners were invited to participate in the study. The researchers had no prior relationships with any of the participants (Table 1).

Interviews

All interviews were conducted in participants' homes to ensure comfort and familiarity.⁽¹⁷⁾ The first author, a male medical student with qualitative research experience, oversaw recruitment and conducted all interviews. The remainder of the research team included a nurse researcher, a geriatrician scientist, and three social scientists, all with experience in qualitative research with people living with dementia. The team developed a semi-structured guide designed to solicit participants' perspectives (Table 2). Minor revisions were made after the first interview to clarify wording of questions and add prompts where needed. People living with dementia were encouraged to partake in the interview separate from their care partners to minimize the impact of relationship dynamics on participants' comfort and openness, but if preferred, both were interviewed together. Repeat interviews were conducted if the participants indicated they wanted more time to review the list of quality indicators.

Analysis

We used a descriptive content analysis to analyze the interviews which were transcribed verbatim. Identifying information was removed in the transcription process. Analysis occurred concurrently with data collection using a coding manual that was developed after the first interview and then iteratively revised.⁽²²⁾ Content analysis was used to explore themes in the transcripts by coding common ideas and thoughts.⁽²²⁾ During this process, we stayed close to the data and focused on the description of participants' perspectives, avoiding interpretation where possible. We achieved data saturation when no new codes or themes emerged in consecutive interviews. The authors met in-person to refine

identified themes by grouping similar concepts and creating subthemes until consensus was achieved with regard to the final set.⁽²²⁾ We also coded transcripts from two dyads together to ensure consistency in the meaning of themes. The rest of the transcripts were independently recoded using the finalized themes. Finally, we conducted a member check with two participant dyads to identify any incongruencies with the themes we identified.

RESULTS

A total of 17 participants were interviewed: 9 interviews with persons living with dementia and 8 interviews with care partners. Most participants were recruited from Alzheimer Society programs. The mean age of those living with dementia was 75 years old (range: 59–99 yrs), with 4 males and 5 females. The mean Functional Activities Questionnaire score for participants at the time of the interview was 16, ranging from 0 (completely independent) to 30 (entirely dependent on others), suggesting that most needed some assistance with activities of daily living. All participants living with dementia, except one, had obtained post-secondary education. Most care partners were spouses of persons living with dementia. One participant did not have a care partner. Of participants living with dementia, five had been assessed by specialists (neurologists or geriatricians), while four were seen in interdisciplinary primary care-based memory clinics.

Through the content analysis, four major themes emerged:

1. Person-centred care as “seeing me as a person”;
2. Person-centred care’s connections with quality of care;
 - 2a. “I hope that the people looking after me know about me;”
 - 2b. “I like to understand [what’s happening] as we go down the road;”
 - 2c. “The doctor doesn’t even know all the resources that are available;”
3. Need for self-advocacy to receive person-centred care; and
4. Quality indicators as reasonable but “not all of it”.

The themes and subthemes are described in detail below.

1. Person-Centred Care as “Seeing Me as a Person”

Participants described person-centred care as the clinician’s recognition of the person behind the diagnosis of dementia. Rather than just being perceived as a patient diagnosed with a condition, participants talked about the importance of being perceived by clinicians as a “regular person” (participant 6 living with dementia, page 1, [6P, 1]). Both people living with dementia and care partners consistently indicated that recognizing the individual was crucial to person-centred care. A care partner describes this as: “He isn’t the disease; he’s still the person he was before.” (care partner 7, page 7 [7C, 7])

Several participants discussed the impact that clinicians

TABLE 1.
Participant characteristics

<i>Participant</i>	<i>Age (yrs)</i>	<i>Sex</i>	<i>Highest Education Level Attained</i>	<i>Functional Activities Questionnaire Score</i>	<i>Main Care Partner</i>	<i>Physician Referred to for Cognitive Impairment</i>
PWD 1	59	Female	Post-secondary	0	None	Specialist
PWD 2	74	Male	Post-secondary	20	Spouse	Specialist
PWD 3	86	Female	Post-secondary	19	Daughter	Specialist
PWD 4	73	Male	Post-secondary	10	Spouse	Memory clinic
PWD 5	79	Male	Elementary	10	Spouse	Memory clinic
PWD 6	69	Male	Post-secondary	26	Spouse	Memory Clinic
PWD 7	78	Male	Post-secondary	14	Spouse	Specialist
PWD 8	60	Female	Post-secondary	15	Spouse	Specialist
PWD 9	98	Female	Post-secondary	30	Niece	Memory clinic

PWD = person living with dementia.

TABLE 2.
Interview guide

1. What is important to you when it comes to your care?
2. What does person-centred care mean to you? How does person-centred care look to you?
3. Do you think person-centred care is important to high-quality care?
4. How do you think person-centred care contributes to the quality of your care?
5. Do you think quality indicators are consistent with what you think of as person-centred and high-quality care?

providing person-centred care can have. They talked about clinicians who “treat you like you matter” (7C, 8) and help them feel like “[they] still have some value” (2P, 4). Two different participants described how they “haven’t felt as though [they were] just a number” (7P, 2) because of clinicians delivering person-centred care.

“Being treated like a human and not like a number. It makes a big difference just even the least bit of personalized care. It makes a big difference in how you feel.” (8C, 6)

However, some participants felt that the current care settings and practices limited person-centred care:

“... it’s too impersonal, because you’re in this huge hospital-like setting and they don’t have the time to find out what [my husband] is all about, what his interests are, what he needs specifically, what kind of music he likes to listen to, what specific foods he likes to eat. Does he like to be outside? Does he like to be inside? To me, I think that’s really important.” (4C, 3)

The recognition of the individual person was not always a priority in existing care processes, as exemplified by the care partner discussing the lack of time available to get to know her husband as more than a patient with dementia. Person-centred care, as perceived by participants, is one in which “the most important aspect of the care involves the individual, the person, not the clinicians.” (6P, 2) Both persons living with dementia and their care partners described person-centred care, which they defined as seeing or knowing them as a person, as crucial to quality of care.

2. Person-Centred Care’s Connections With Quality of Care

Quality of care was not explicitly defined for participants and they were encouraged to use their own perspectives to inform their answers. Participants all indicated that person-centred care was essential to providing high-quality dementia care. They described how lack of person-centred care resulted in poor quality and negative outcomes:

“One cannot bypass [person-centred care] without losing a great deal of potential treatment value. So, yes. It’s so central, so important, that if you don’t talk about it, you don’t deal with it, you’ve not only lost the opportunity to be helpful, you may have actually left the patient harmed.” (6P, 4)

Under this major theme, we identified three subthemes that describe the perceived connections between person-centred care and quality of care: a) “I hope that people looking after me know about me”, b) “I like to understand [what’s happening] as we go down the road”, and c) “The doctor doesn’t even know the resources available.”

2a). “I Hope That People Looking After Me Know About Me.”

Clinicians’ ability to solicit what is important to persons living with dementia and their care partners—which can

include concerns, needs, and values—was described as key to delivering high-quality, person-centred care. Two individual participants living with dementia expressed this as follows:

“I would hope the people looking after me know about me. And know what my limitations are. And don’t push me into doing things that I don’t feel comfortable doing.” (2P, 4)

“Well I think, you need to clearly sit down and talk to somebody. Who spends enough time with you to find out what your concerns are, what your fears are.” (6P, 5)

Some participants described how person-centred care—and therefore high-quality care—was impossible if one did not understand the impact dementia has had on the person’s life.

“I suspect that in my experience, some of the clinicians or people involved in my assessments weren’t even aware of the fact that I’m a PhD in _____. I’m forgetful now, I don’t express myself very well, but it’s very important ... what was important to you. Where I spent 30 years is not even touched upon in most cases ... You’re going to be dealing with losses and difficulties that are particular to you. And some of the clinicians won’t even ask the question: “Where were you before? What did you do with your prior life?” (6P, 1)

The solicitation of what is important to a person living with dementia was viewed by participants as something that must be done promptly by clinicians, before the cognitive decline associated with dementia made this difficult.

“I think the secret is to get at the patient early enough when he can still advocate for himself or herself, and answer questions and tell the doctor.” (4C, 9)

Listening to people living with dementia and their care partners, as well as asking questions about one’s life, were recommended as simple but effective strategies to solicit what is important to people. A care partner discussed the value of having “somebody [that] has the time to just be with them—not fixing them or changing them.” (7C, 8) This idea was reiterated by other participants as an important part of providing care and services to persons living with dementia:

“It’s very important that the doctor listens to the person who is living with the patient. And he [the doctor] was not listening. And I kept thinking, he doesn’t live with [my husband]. He sees [my husband] for maybe 5 minutes at a time. So he has no clue what goes on inside the home ... we’re the ones living with the patient.” (4C, 1)

“They (clinicians) spent time with you, and they spent time with [my son] and I, asking questions. Asking questions about my life and about [my husband]. And that’s how you find the things out, by asking questions.” (4P, 11)

Similarly, a care partner noted their physician’s tendency to “just observe”, which improved her confidence in the quality of her husband’s care.

“Just observe. I feel encouraged by it because he doesn’t immediately say, ‘[something].’ I can just see that he’s

assessing the situation ... I just find it comforting. And I don't ask a lot of questions, I never have. I just trust every time he does something, or they offer something, or they recommend something, I just feel fine." (6C, 1)

Participants had various perceptions of certain clinicians' role in delivering person-centred care. Many saw person-centred care as the purview of primary care providers, while specialists were expected to "manage" the "clinical" aspects of dementia.

"[Nurse practitioners] seem to have a mandate to do [take their time with patients]. I don't know why the doctor doesn't have that same mandate. But I appreciate the fact that my mother sees a nurse practitioner." (3C, 4)

Participants indicated that specialists' approach could be improved by integrating person-centredness:

"The things [my neurologist] is looking for are higher functioning and the things that I do everyday are things that my family doctor would be responsible for. And I'm happy with that—in that way. I'll go to him [neurologist], and I'll go, 'Oh God, let's get this over with.' And then tomorrow, 'Hi [name of family doctor], how are you doing, how are the kids? Blah blah blah ... okay, what are we doing?'" (1P, 5)

Participants' comfort with their physician influenced their willingness to share what was important to them. Unfortunately, some participants recalled negative experiences when they attempted to share their thoughts with clinicians.

"The [physician] tells me, 'Do you not think I know?' Yeah, he was pretty upset with me, because I was pretty upset with him, because I thought my husband was going down, down. He was going down and he [physician] didn't seem to really look into it and do something so that things could get better. So I was upset with him and he was really upset with me ... I mean, you don't "tell" him [the physician], you got to suggest or ask in a nice way, so that you're not really telling him. Then maybe they'll listen to things." (5C, 10)

Participants described that understanding what is most important to the person living with dementia as the key to integral high-quality, person-centred care. The following two subthemes shed light on how this principle relates to practical aspects of person-centred care.

2b. "I Like to Understand [What's Happening] as We Go Down the Road"

The second subtheme that connects person-centredness with quality of dementia care is effective and appropriate communication to engage the person living with dementia to be "part of the process" (2P, 9).

"It's engaging to help [them] understand what they're experiencing." (2C, 5)

Participants' described how negative experiences with clinicians' communication harm the therapeutic relationship.

"My regular doctor is an [expletive], pardon me. He really is. The only thing he ever said to me was: 'You know what is going on?' And I didn't obviously. And he said, 'You won't see a cure in your lifetime. And the phlegm will go in here, and that's the way you'll die'... What do you say about that guy?" (8P, 1)

In reflecting on their experiences—both positive and negative—with communication, participants listed specific considerations for clinicians when communicating with persons living with dementia. For example, a care partner described the importance of directly addressing the person living with dementia in discussions:

"I know my family doctor usually looks at me [care partner], and I'm going to have to tell him, 'Don't look at me, look at him [husband], because he's the one you're treating, it's not me.'" (5C, 4)

A participant living with dementia discusses the anxiety that is provoked and the barriers that they face when speaking with clinicians.

"Because once you have dementia, all of a sudden you can't answer questions you could before. And you get asked a question and you can't remember the answer. Then you feel stupid. Then you start to shut up. I'm not going to answer any because I may make a mistake and I'm gonna feel like a fool because attention would be drawn to it." (2P, 6)

Participants described another common barrier to communication, that is, the use of technical and clinical language. Participants felt that it was key for clinicians to "be able to talk to the person at their level" (3C, 8).

"The specialists people do special things. So when they're talking to the normal people. They don't realize that we don't understand the words that they're saying. So they need to have a more ... an easier conversation ... that it isn't so clinical." (1P, 10)

The effectiveness of clinicians' communication has an impact on participants' understanding of their care and condition. Many people living with dementia and care partners were hoping for more clear conversations about what to expect. One care partner described this as crucial to develop a "game plan" (3C, 6):

"I just like to understand as we go down the road. I don't understand, I don't know because I'm not a doctor and I haven't studied it, how long it'll take her to get to another stage. But I'm the kind of person who has a plan A, plan B, and usually a plan C just in case. I feel sometimes that ... the information is not in one place." (3C, 3)

This subtheme highlighted how understanding the persons living with dementia's values can contribute to positive clinical interactions through effective and appropriate communication. Similarly, the next subtheme relates to how knowing the values, concerns, and needs of the person living

with dementia can impact the quality of care on a system level that extends beyond specific clinical encounters.

2c. “The Doctor Doesn’t Even Know the Resources That Are Available”

The last subtheme related to the links between person-centred care and quality of care was the navigability of health and non-clinical resources. Continuity of care, particularly communication between clinicians, was recognized by participants as crucial to providing person-centred care.

“[Our family doctor and geriatrician] talk to each other. And when I say talk to each other, I think they actually talk to each other as well. That’s one thing that I find really comforting. Person-centred care is that.” (6C, 6)

A participant describes how gaps in the health-care system make it difficult for a person living with dementia to navigate.

“There isn’t sufficient sharing between medical systems. [It] is also ... again, another reason why a person like me has to take a book ... So [home care] has been here for my husband and my mother. And so, when we go in to see the nurse practitioner for my husband, nothing came back from [home care] to her. So I have it. I say, ‘here it is.’ This is what happened ... [.] And if a person has to remind their doctor all the time that we did this, we’re doing that, that’s okay for a person without dementia. It’s not going to work for a person with dementia. [...] ... communication is paramount to make sure that everybody knows that the things they’re doing are all to aid the patient.” (3C, 10)

Participants who received care from interdisciplinary primary care-based memory clinics felt that the team-based approach contributed to the quality of their care.

“For example, if at one point we need to go in about diet, I know we can go there. And you can also go to one centre. It’s all in one place. So it’s familiar to the patient, especially for a patient with dementia who doesn’t want to go to different locations all the time. I think that helps as well and it helps me.” (6C, 4)

Participants felt that clinicians were optimally positioned to help them navigate the many and often disjointed resources for dementia. However, several felt that physicians were not well-versed in local resources available for persons living with dementia.

“But the doctor doesn’t even know all the resources that are available. I think it’s really important. Even if we only get a 20-minute interview. He could say, ‘well, there’s this you can do, there’s this, this, and this.’ If he knew these things, if he or she was made aware of these things, I think it would be really very helpful. At least it would feel like he was in your corner.” (4C, 5)

“It would be nice if [my neurologist] could go to a session with the [support group for persons living with dementia] just to see what happens there.” (1P, 8)

Non-clinical resources such as the Alzheimer Society were valued by participants who accessed them. They emphasized the need for people who are newly diagnosed to be connected to these programs and emphasized the role of clinicians as facilitators.

“[Clinicians] should have a very good understanding of the whole support system that’s available for people with dementia. They really need to have that. And to realize that they are the ones in the position to help people start on that journey of understanding and accepting what’s going, and how to link with resources and how important that’s going to be to them.” (2C, 8)

“If they’re not aware of [the Alzheimer Society], then they shouldn’t be a doctor in this field. That’s how much I feel about that.” (2P, 6)

This subtheme demonstrated how person-centred care, as understood by participants, extends beyond individual clinical interactions and connects with system-level factors to impact quality of care. The next themes relate to participants’ experiences with the health-care system, and their feedback on quality indicators developed by clinicians.

3. Need for Self-Advocacy to Receive Person-Centred Care Within a Resource-Constrained System

Self-advocacy was described by participants as crucial for them to receive person-centred care within a resource-constrained health-care system. Many felt that the responsibility fell on them to advocate for high-quality care for dementia.

“I have to be proactive and push. So you just approach it ... it’s like okay ... I need to have this organized, and if they’re not gonna do it, you push them until they put you to somebody else.” (4P, 3)

Several care partners proudly exhibited tools and strategies that helped them advocate for their family member living with dementia. Said one: “I’ve got a whole binder on his health. I’ve been keeping track, I tell you.” (5C, 7)

“So when I go to the doctor and say, ‘I think my husband is suffering from depression.’” [And my doctor says,] ‘He can’t be depressed. He’s fine, he’s fine!’ So for three years, I dealt with this until finally [my husband] came with me and we presented him with a list of things that [my husband] and I prepared together enumerating things that both of us found ...” (4C, 1)

Participants described “holes in the system” (8C, 11) that impeded the delivery of high-quality care. Limitations in physicians’ time and financial resources were most commonly cited barriers to person-centred care.

“A normal appointment time is 10 minutes. 10 minutes. Now, with us, it goes longer because we don’t get up off the chair. That’s what they strive for, 10 minutes. Write a prescription, take the pill, good bye.” (4P, 3)

“I really felt that we could have saved money if we just sat down and really listened to people about what they

really needed. Because a lot of the time it wasn't anything that cost money, it was listening. Being hooked up with people that can be supportive, and agencies." (2C, 3)

When asked for potential improvements to person-centred care, participants' ideas ranged from system-level changes, such as a "total change of culture" (6P, 4) to individual training.

"The whole system needs a whole quantum shift and it's gonna involve everything that's tied into it [referring to policymakers and clinicians]." (4P, 15)

"... the demographic is such that there's so many more older people. And much more prevalence, as far as memory loss and dementia. They have to start teaching [person-centred care] in medical school, that this is gonna be a big, big part of your practice. This is what you're going to have to learn." (4C, 14)

4. Quality Indicators as Reasonable but "Not All of It"

Participants felt that the set of quality indicators presented to them were "reasonable" (1P, 9) and represent "good quality care" (8C, 10). When asked to provide feedback on specific indicators, discussions revolved around the trust placed in clinicians to be capable of providing high-quality care for dementia.

"Well, obviously the person [clinician] needs to know what they're doing. To me that's a given. And I trust that our medical system has ways and means of rooting out people that are less qualified and directing them to places that they can be a benefit and can use their skill set." (3C, 10)

A lack of expertise about clinical dementia care was cited as a reason for "not having an opinion" (3C, 15) on quality indicators.

"I've tried to talk to [my husband] and I don't think he can be specific. And I don't think he's got very good understanding of his medications really." (2C, 10)

"Asking what my mother thinks about medications for memory. Is that high-quality care? Probably not, because she doesn't know." (3C, 14)

Several participants provided feedback on specific quality indicators related to advance care planning, assessments, and investigations, and follow-up/medication reviews (Table 3). When discussing advance care planning quality indicators, participants felt that it was important to begin the process early while persons living with dementia were still capable and relatively healthy. However, questions arose about the necessity of frequent assessments (e.g., cognitive tests) and investigations that can be associated with distress and tension in the provider-patient relationship. Lastly, participants had different perceptions for appropriate length of follow-up while all appreciated medication reviews.

Many felt that quality indicators do not completely capture high-quality and person-centred care. Nonetheless, participants believed that the quality indicators provide a starting point for clinicians.

"If my physician did everything on this list [referring to the quality indicators], it would be a good start. I think they still have to get to know the person ... Something that's more personable, more human, more to the person as opposed to the medicine, I think that would be a huge, huge improvement." (4C, 12)

Nonetheless, participants felt that quality was important to measure and suggested interviews to measure quality of care: "Talk to them. It's very simple and very basic [on how to measure quality of dementia care]." (4C, 13)

TABLE 3.
Demonstrative quotes of participants' feedback on quality indicators related to advance care planning, assessments and investigations, and follow-up/medication reviews.

<i>Quality Indicator Category</i>	<i>Participant Feedback</i>
Advance care planning	You, your family, carer understand your wishes if you get sick. You expect that. (1P, 10) I think the secret is to get at the patient early enough when he can still advocate for himself or herself and answer questions. And tell the doctor. (4C, 9)
Assessments and investigations	I guess making a point of giving the patient an opportunity to express what they're experiencing before assuming that, "Okay, this person doesn't do very well on this particular test, therefore, must be..." There could be a place for that as well, but how does that line up with what the patient is experiencing? (7P, 5) Well if I'm going to [my neurologist], I'm going to be tense. I know I'm going to be tense because I know he's going to be testing me. (1P, 6) My husband undergoes standard imaging (CT scans) and blood tests. That one I'm not sure about because it's very stressful for them, for him to get that done. (6C, 6)
Follow-up and medication reviews	I think a year is too long to be reassessed. (5C, 13) I think that reassessed by a doctor within 1 year, I think 1 year is a bit long. That's a bit long. (6C, 6) When we go see the doctors, I think it's very important that they look at the medication he's already on. We also think it's very important to say, "hey, do I have to give him another pill? Is there something alternative that might help him?" (5C, 1)

DISCUSSION

We explored person-centred care and quality of care from the perspectives of persons living with dementia and their care partners. Our participants defined person-centred care as care that did not focus only on clinical aspects of dementia but also recognizes and values the person. This finding is consistent with the late Tom Kitwood's oft-cited definition of person-centred dementia care that focuses on valuing persons, treating them as individuals, seeing the world from their perspective, and ensuring a positive social environment.⁽⁴⁾ This definition has been explored and applied extensively in residential care,⁽²⁴⁾ but it is often used within the context of ambulatory care settings. It is noteworthy that our participants believed that clinical settings are not optimized to deliver person-centred care. Nonetheless, all participants believed that person-centred care was essential to high-quality dementia care. This supports the well-entrenched belief that person-centred care in dementia is closely tied with quality of care.^(4,6)

The subthemes that emerged connecting person-centred care with quality of care are concurrent with previous research on patient experiences with dementia care.⁽³⁾ However, our study is one of the first to explicitly link these experiences with person-centred care and quality of care. Of the three subthemes we identified connecting the two concepts, the theme related to clinicians' ability to solicit what was important to patients—"I hope people caring for me know about me"—appeared most important. We suspect this is due to the link between what is important to patients and their identity as a person, which was central to most participants' understanding of person-centred care. This principle has been described in the context of a nursing approach in residential care⁽²⁵⁾ and primary care⁽²⁶⁾ which considers both the clinical agenda and the relationship with the patient. Finally, to our knowledge, it is a novel finding that participants living with dementia experienced and perceived person-centred care as generally the responsibility of primary care providers and outside of the purview of specialists. Participants' experiences appear to associate primary care with "relationships", while visits with specialists were perceived more as "encounters".⁽²⁷⁾ The emphasis of a longitudinal patient-physician relationship in primary care may be a driving factor for this difference.⁽²⁸⁾

The second connection we identified between person-centred care and quality of care was, "I just like to understand [what's happening] as we go down the road"—emphasizing effective and appropriate communication. This subtheme is consistent with other literature that reports ineffective communication can lead to dissatisfaction among both persons with dementia and their care partners.⁽³⁾ Past studies have also described the navigability of health and non-clinical resources for persons living with dementia and their care partners,^(3,29) a sentiment echoed in the third subtheme—"But the doctor doesn't even know all the resources that are available."

Lastly, our participants reported the importance of self-advocacy in receiving quality care, a view shared by participants in a recent qualitative study also in Ontario, Canada.⁽³⁰⁾

In addition to concurrent findings, we also found that patients and care partners provided insight into system issues, such as resource constraints, that can impede person-centred care. Interestingly, clinicians also reported similar system issues related to financial and human resources when interviewed in a separate study examining barriers to quality assurance in dementia care.⁽³¹⁾ While our results suggest that an integrated system of primary care, specialists, and community supports may be well-suited to deliver high-quality, person-centred care, systemic barriers need to be overcome to achieve this.

Our participants provided feedback on quality indicators after discussing their perspectives on person-centred care. Despite feeling that the set of indicators was reasonable, many hesitated to provide input on specific indicators due to their perceived lack of technical/medical expertise. Further, participants felt that they can trust clinicians to provide high-quality care and thus their input was not needed. However, we found that participants readily provided insight on non-clinical quality issues, such as advance care planning, feelings surrounding assessments, and length of follow-up. When developing quality indicators in lung cancer, Hermens et al.⁽³²⁾ similarly found that, while patient representatives faced barriers when assessing technical/medical quality, they provided valuable feedback into other aspects of care, such as follow-up and organization.

Several aspects of participant feedback on quality indicators are worth highlighting. Most notably, we found that participants valued early advance care planning, in contrast to clinicians we previously surveyed who viewed these discussions with patients with mild disease as premature.⁽²¹⁾ Similarly, a recent survey reported that, while clinicians working in primary care-based memory clinics believe that advance care planning is important, this does not necessarily result in their completion.⁽³³⁾ Furthermore, some participants viewed assessments (such as cognitive testing) and investigations negatively. Perhaps influenced by discussions of person-centred care earlier in the interview, they questioned the need for regular formal assessments, especially when these were experienced as stressful. Participants felt that if the clinician knew of the patient as a person, these assessments may not always be needed. Finally, we were surprised that participants felt quality indicators represent only a small part or "starting point" for high-quality and person-centred care.

Taken together, our findings suggest that there are limits to traditional quality indicators that rely largely on technical/medical aspects of care. Our participants' emphasis on what is important to persons living with dementia rather than technical disease-specific metrics supports the use of tools not traditionally used in quality improvement.⁽⁸⁾ One possible template towards person-centred, high-quality care is narrative medicine, which at the core emphasizes clinicians listening and witnessing—but creative ways are likely needed to integrate it into quality improvement and assurance.⁽³⁴⁾ One way to accomplish this may be goal-attainment scaling, a metric increasingly used with persons living with dementia, that may be a meaningful person-centred indicator in addition to traditional quality indicators.^(8,35,36)

Our findings have important implications when involving persons living with dementia and care partners in quality indicator development. First, this study supports the value of involving persons with dementia and care partners in the process. Second, there are barriers unique to involving persons living with dementia that must be considered, such as their likely lack of technical/medical expertise.⁽¹⁹⁾ Their roles must be clearly outlined during the process so that their perspectives can be effectively integrated into the quality indicators. For example, when developing a recently published quality standard for community dementia care, persons living with dementia and their care partners were included as part of Health Quality Ontario's expert advisory committee that guided the creation of the standard.⁽³⁷⁾ Lastly, clinicians and persons living with dementia may have different perspectives on what constitutes high-quality care. This study revealed differences between quality indicators identified by clinicians⁽²¹⁾ and participants' perspectives on what is important to their care. Further research is needed to identify best approaches to reconcile these different perspectives. Relationships between person-centred dementia care, quality indicators, and innovative non-traditional metrics and paradigms, such as narrative medicine and goal attainment scaling, may warrant exploration.

Limitations and Strengths

Our study should be understood in consideration of its limitations. The generalizability of our study is limited due to the nature of our sample. Firstly, all participants were recruited from a single geographic region in Ontario with a universal health care system. Our results may not apply to regions with different clinical resources and practice patterns. Secondly, our participants were highly educated, with all except one having attained post-secondary education, and all were able to converse fluently in English, and were white. Lastly, most participants were recruited from Alzheimer Society programs through active recruitment. Therefore, there may be a sampling bias towards individuals who have prior knowledge of person-centred care and quality of care through these programs. However, only a few participants reported previous exposure to the concept of person-centred care, with none discussing prior encounters with quality indicators.

Nonetheless, our study has several strengths that inspire confidence in our findings. Most notably, we interviewed persons living with dementia which helps fill the gap in literature that involves them in research⁽¹⁸⁾ and quality indicator development.⁽¹⁹⁾ Furthermore, to the best of our knowledge, this study is one of the first to explicitly explore the links between person-centred care and quality of care for dementia. Our findings support current literature, but also contribute to the body of evidence by connecting person-centred care, quality of care, and quality indicators. There were also strengths in our methodology. We conducted interviews in participants' homes to maximize comfort with discussions. Repeat interviews were also conducted with participants who wanted more time to review the quality indicators to help ensure that

they were prepared to provide feedback. Our qualitative description approach with content analysis allowed us to report participants' perspectives as close to their words as possible, increasing our confidence that our results reflect their actual perspectives. Moreover, we conducted member checks with a few participants to enhance the trustworthiness of our analysis. Finally, our sample consisted of individuals who saw different clinicians, from specialists to primary care, which contributed to the diversity of experiences reported.

CONCLUSIONS

We successfully solicited the perspectives of persons living with dementia and their care partners on person-centred care and quality of care. Person-centred care was viewed as the care that focused on individuals, rather than the medical or clinical aspect of the condition, which all participants believed was important to high-quality care. We identified three sub-themes from participants' thoughts on how the two concepts are related, with the most important being clinicians' ability to solicit what is important to persons living with dementia. However, difficulties in navigating current care resources, often attributed to systemic barriers, are thought to impede person-centred and high-quality dementia care. Our participants thought quality indicators reflected technical/medical aspects of dementia care, rather than person-centred care and thus only represented a small part of high-quality care. Future research is needed to explore strategies to better integrate the perspectives of persons living with dementia and clinicians in quality improvement and assurance efforts.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood the *Canadian Geriatrics Journal's* policy on conflicts of interest disclosure and declare there are no conflicts of interest.

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Correspondence to: George A. Heckman, MD, FRCP(C), Schlegel-UW Research Institute for Aging, School of Public Health and Health Systems, University of Waterloo, 200 University Ave. West, Waterloo, ON N2L 3G1
Email: ggheckman@uwaterloo.ca