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RESEARCH ARTICLE



"I'm still in the lap of the gods... I don't know whether I'm going to improve or not": listening to people with dementia or cognitive impairment and their support people, talking about inpatient rehabilitation experiences

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ABSTRACT

Purpose: People with dementia often experience poor outcomes in hospital and prolonged lengths of stay. They are sometimes labelled as having "poor rehabilitation potential". This study aimed to understand the inpatient rehabilitation experiences of people with dementia or cognitive impairment, and their support people, to inform future work to improve rehabilitation access and outcomes.

Materials and methods: An exploratory qualitative study from an interpretivist perspective. Participants were inpatients of a geriatric rehabilitation unit in Australia, and their chosen support people. Semi-structured interviews were audio-recorded and transcribed. An analytical framework was developed and indexed to the dataset, followed by charting and thematic analysis.

Results: Ten people with dementia or cognitive impairment and nine support people participated ($n=19$). Four themes were identified representing an interpretation of the analysis intended to inform clinical practice: *Support patients to engage in the rehabilitation process; create a hospitable environment; recognise and work with care partners; and ensure staff have adequate dementia knowledge.*

Conclusions: Practical, emotional, process-related, and dementia-specific factors may influence the experiences of people living with dementia or cognitive impairment when participating in inpatient rehabilitation. Future research could investigate whether improvements focused on these factors might enhance quality of care for people with dementia.

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► IMPLICATIONS FOR REHABILITATION

- People living with dementia may require tailored support to engage in the rehabilitation process effectively.
- Safe, kind, and comfortable environments provide a strong foundation for good rehabilitation care for people with dementia or cognitive impairment.
- Involving family as care partners may be essential for some people living with dementia.
- Dementia knowledge for the geriatric rehabilitation workforce may improve clinical outcomes.



Introduction


People with dementia often experience poor outcomes and long lengths of stay in hospitals due to complications, multimorbidity, and the complexity of care required [1,2]. As the number of people living with dementia is expected to rise to over 150 million globally by 2050 [3], identifying ways to improve these outcomes is vital for people living with dementia and for the sustainability of global health systems. One way to improve health outcomes after illnesses such as stroke, falls, or functional decline in hospital, is rehabilitation [4].

Dementia advocates have called for rehabilitation to be considered a human right [5], yet people with dementia are often denied the opportunity to participate in rehabilitation, deemed

by health professionals as lacking rehabilitation potential [6,7]. It is difficult to ascertain whether this perspective is informed by ageism, dementia stigma, or lack of expertise in dementia care [2,4], as there is research evidence available to support the effectiveness of rehabilitation interventions for people living with dementia [8]. This evidence is limited, however, as dementia and cognitive impairment are often exclusion criteria for research, even research in the field of gerontology [9].

Despite the barriers to access, some people with dementia are admitted to rehabilitation programmes, particularly geriatric rehabilitation units. Understanding which aspects of current rehabilitation practice are working well for people living with dementia,

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and which could be improved, may help inform the development of future rehabilitation models and shift mindsets that may limit access to rehabilitation for people with dementia. The perspectives of people with dementia admitted to geriatric rehabilitation units and the views of their families [10] should form the foundation of any work in this area. This is particularly important given the high prevalence of comorbidities, such as stroke and diabetes amongst people living with dementia [11], which frequently lead to hospitalisation and a need for rehabilitation. However, the opinions of people living with dementia are seldom heard [12,13].

Qualitative studies investigating the opinions of people living with dementia about rehabilitation are few, and primarily focused on settings other than inpatient rehabilitation. For the community setting, perspectives of people living with dementia and their care partners regarding post-diagnostic rehabilitation have been published [14], indicating poor access to rehabilitation services, and an interest in participating in relevant rehabilitative therapies. In the acute hospital setting, views of people with dementia have been reported regarding the implementation of new models of care [15] or environmental design features [16]. For the inpatient geriatric rehabilitation setting, a scoping review by Lubbe et al. on the quality of rehabilitation from the perspective of patients found, amongst the 20 included articles, only one article with one participant living with dementia [13].

Therefore, this study aimed to contribute knowledge to improve inpatient rehabilitation access and outcomes for people living with dementia, from the perspectives of people living with dementia and their support people, by answering the following two research questions:

1. What are the experiences of people with dementia or cognitive impairment, and their support people, when participating in inpatient rehabilitation?
2. How can inpatient rehabilitation units improve rehabilitation access and outcomes for people with dementia?

Methods

Design

This study was guided by qualitative methodology from an interpretivist perspective. Research from an interpretivist perspective seeks to understand the views of people who have experienced a particular phenomenon. In this study, the experience of rehabilitation is from the perspective of people living with dementia and their support persons. An interpretivist view acknowledges that the standpoint of researchers influences the approach to the study design, data collection, and analysis approach [17].

We chose interpretive description as an analysis approach as it seeks to examine qualitative findings and their application to real-world clinical scenarios to improve patient care or quality of life; this aligned firmly with our research questions and research team values. Interpretive description is a flexible approach for applied health disciplines. It proposes a process of inductive reasoning starting with data sorting and then identification of patterns and relationships, moving on to transformation of the data with the research question and clinical reader in mind. Exact analytic steps are not prescribed and the drawing of inspiration from research methods stemming from other qualitative research paradigms is encouraged, with choices informed by disciplinary logic [18].

The study was approved by the Tasmanian Human Research Ethics Committee and has been reported with reference to the COREQ guidelines for qualitative studies [19].

Participants

Participants were recruited in dyads of a patient with dementia or cognitive impairment and their support person, such as a family member or friend. In this article, participants are referred to as “patients” and “support people” to distinguish between these groups. Eligible patients admitted to a geriatric rehabilitation unit in a regional city in Australia were identified by clinical staff and provided with an information and consent form. Verbal assent was sought from the patient for their name to be passed to the research team so researchers could give more information about the study (in person) and contact a support person identified by the patient (in person or via telephone). Patients were not excluded if they chose not to identify a support person. They could also choose to be interviewed with their support person or be interviewed alone [20].

Inclusion criteria for patients included being an inpatient on the geriatric rehabilitation unit at the time of recruitment and being described by clinicians working on the ward as having dementia, mild cognitive impairment, or cognitive decline. Patients were included in the study even without a formal dementia diagnosis, as dementia is often undiagnosed or unrecognised in the hospital setting [21]. A history of dementia or cognitive impairment was documented in a patient’s medical history or indicated by a Montreal Cognitive Assessment (MoCA) score of <26 [22]. All participants were required to speak English as funding for interpreters was not available.

Regulations in the Australian State within which this study was conducted did not allow proxy consent for research purposes, so all participants were required to be able to provide direct consent. Patients who were still making everyday decisions provided their consent [23]. If patients could not participate in a basic conversation or had a Guardianship Order in place, they were ineligible for the study. A process consent method was adopted to enable inclusive recruitment within legal parameters. This method included seeking advice from clinical staff about each patient and whether it was appropriate to offer them the opportunity to participate, initial consent at the time of signing a consent form, and ongoing monitoring of consent to ensure the person with cognitive impairment still wanted to participate [24].

Data collection

Semi-structured interviews were conducted after patients had been admitted to rehabilitation for at least 7 days. The interview guide is available in [Supplementary Appendix 1](#). Interviews were conducted at the bedside for patients in a single room, or in another quiet room on the ward. They were audio-recorded and transcribed verbatim. Participants were encouraged to be open with their views, as the research team was looking for ways to improve care on the ward, which included understanding what was working well and what could be better. They were advised their data would be de-identified and combined with data from other participants.

Data analysis

We used framework analysis methods to sort the data and identify initial patterns [25]. Transcripts were read multiple times by paired researchers involved in the analysis at the familiarisation stage. Multiple rounds of coding interspersed with analytical team meetings were conducted at the analytical framework creation stage. Initial coding rounds used an *in vivo* coding lens to identify and represent concepts in the words of the participants to align with

the project team's intention to elevate the voices of people living with dementia to be heard. Subsequent coding rounds used a *values* coding lens to identify the attitudes, values, and beliefs expressed by participants. Coding lenses were drawn from the descriptions presented by Saldana [26]. The finalised analytical framework (Table 2) was then used to index the entire dataset using NVivo software [September 2022 (Release 1.7), QSR International Pty Ltd.]. This framework described the experiences of people with dementia or cognitive impairment, and their support people, answering the first research question.

Following indexing, matrix analysis and hierarchical charting tools in NVivo were used to explore and extend the data analysis. Finally, the identified categories were mapped to themes. In keeping with interpretive description methodology, the clinical reader was in mind when researchers were interpreting the descriptive data and choosing words to describe the themes [18], asking themselves the question "What does this mean for clinical practice?" [27]. Therefore, the final themes represented an interpretation of the analysis that presents the findings with the intent of informing clinical practice. These themes answered the second research question.

The research team and reflexivity

Interviews were conducted by physiotherapists [SS and KL] with clinical experience in rehabilitation who were not working on the recruitment ward at the time of data collection. As this research was conducted from an interpretivist perspective, the research team practiced reflexivity using a team-based approach [28]. This

was important to ensure the research team remained cognisant of their views and values throughout the data analysis. Detailed information about the interviewers and the broader research team is available in a reflexivity statement (Supplementary Appendix 2).

Results

There were 19 participants in the study, inclusive of 10 patients and nine support people (Table 1, Supplementary Appendix 3). Two patients did not nominate a support person for an interview, and one patient selected two support people. Fourteen interviews were conducted between 14 October 2021 and 1 July 2022 with the patient alone ($n=6$), the patient and support person together ($n=4$), support people alone ($n=3$), and support people together ($n=1$). The first eight interviews were conducted without masks. The remaining interviews were conducted with masks *in situ* for interviewers and participants due to COVID-19 pandemic restrictions. A total of 432 min of interview data were collected. At the time of the interview, patients had been in the rehabilitation unit for a median of 27.5 days (range: 13–76 days). Quotes from patients have been labelled "P" and support people "S".

The analytical framework answered the first research question and included eight categories (Table 2). From these categories, four cross-cutting themes were identified to answer the second research question. The themes were: (1) Support patients to engage in the rehabilitation process; (2) Create a hospitable environment; (3) Recognise and work with care partners; and (4) Ensure staff have adequate dementia knowledge. A sample of the coding tree is available in Supplementary Appendix 4.

Table 1. Participant characteristics.

Patients with dementia or cognitive impairment						Support people			
Identifier	Age (years)	Gender	MoCA (/30)	Reason for admission	Likely discharge destination	Identifier	Age (years)	Gender	Relationship
P1	83	Male	22	Fall/fractured lower limb	RACF ^a	S1	51	Female	Daughter
P2	84	Male	17	Pain and weakness lower limb	Home with spouse	S2	82	Female	Spouse
P3	89	Female	19	Fall/fractured lower limb	RACF ^a	S3	62	Female	Daughter
P4	78	Male	25	Fall/fractured lower limb	Home with spouse	S4	67	Female	Spouse
P5	84	Female	12	Medical events, deconditioning	Home alone				
P6	75	Female	24	Stroke	RACF ^a	P6a	51	Female	Daughter
P7	82	Female	24	Fall/fractured lower limb	Home with spouse	P6b	49	Female	Daughter
P8	92	Female	24	Back pain/functional decline	Home with daughter	S7	81	Male	Spouse
P9	86	Male	25	Falls, cognitive decline	Home alone	S8	69	Female	Daughter
P10	81	Female	16	Stroke	Home with spouse	S10	65	Male	Partner

MoCA: Montreal Cognitive Assessment; RACF: residential aged care facility.

^aChange from pre-admission living arrangements and/or the support required at home.

Table 2. Categories and codes in the analytical framework.

Categories	Included codes
Rehabilitation	Rules of rehabilitation; role of health professionals; goals of rehabilitation; understanding rehabilitation.
Hospitality	Staff kindness; quality of staff; food options, food quality; noise; parking; staff responsiveness.
Dementia-specific matters	Role of care partners; understanding the person; insight; staff dementia knowledge.
Autonomy and decision-making	Deferring to health professionals; choice; dignity; discharge planning; advocating for self.
Connection and relationships	Interaction with roommates; interaction with staff; connection with family and friends; left to own devices.
Communication	Feedback on progress; engagement with family; confusing; disjointed; hurried/rushed.
Feelings and emotions	Desire to return home; contentment; best place to be; bored; upset; gratitude; trapped.
Activity	Participating in rehabilitation; sedentary leisure activities; sitting; dining room.

Theme 1: Support patients to engage in the rehabilitation process

The experiences described by participants indicated low knowledge of the rehabilitation process and the purpose of goal setting, participation in therapeutic activities, discharge planning, and the role of health professionals in this context. Additional support to engage in the rehabilitation process may be required to improve rehabilitation outcomes for people with cognitive impairment.

Some patients described their participation in a range of activities, such as making porridge or coffee, attending a home visit with an occupational therapist, gait re-education, and mobility practice. However, more prominent was their awareness of what they perceived to be the rules of the rehabilitation unit. These rules seem to have been frequently communicated with participants, such as restrictions relating to mobility:

I can't move around unless I'm on [my walking frame], and I've got to be attended. You see it says "call, don't fall". Always have somebody around to hold you up. So I obey that little bit of information. (P1)

Other rules included those relating to visiting hours, a particular challenge during the coronavirus pandemic:

I find it rather tiring with all of the visiting. But you are given sort of between 2 o'clock to 6 o'clock, so it's quite generous with the hours. Not 2 to 3 or anything. (S2)

Some patients described most of the day in rehabilitation as guided by rules:

If it's time to eat, I eat. If it's time for me to go to the doctor, I go to the doctor. I don't worry about, no, I'm not going, or no, I can't go. I just do as I'm told. (P3)

Some patients and support persons demonstrated an understanding of elements of the rehabilitation process. For example, some were able to clearly articulate reasons for attending rehabilitation:

Well, a lot of it is repetition, and building on what stages I can reach, to enable me to put full weight on that recovering leg. It might sound simple or even simplistic, but it's absolutely essential. I mean, I could go home and hobble around, but it wouldn't improve long-term. So, I've got to try and make the most of that. (P4)

Even if he goes to a nursing home, he needs to be able to – he doesn't want to be like some of those people that's just laying in bed all day to die, basically. I can see why he has to be here. (S1)

Other patients were less certain, making statements such as:

Well, I suppose they try to teach you to be self-reliant or something. I mean, teaching me, at 80, how to make a piece of toast. I mean, most people have made a piece of toast. I told them I think it was ridiculous, making a piece of toast. But then again, I suppose there are people who have to be shown things. (P5)

Others seemed quite unaware of the concept of rehabilitation, seeing their time in the rehabilitation unit as an opportunity to rest:

I guess you can do things for yourself ... if you want to. And, if you don't want to, well, you don't bother. You think – well, this is my thinking, "I'm in here and they can jolly well bring it to me. That's what I'm in here for." (P3)

Similarly, although most patients expressed that their main goal was to go home, there seemed to be a disconnect between what they saw as the purpose of rehabilitation, or how pleased they were with their experience in the rehabilitation unit, and

their likely discharge destination. Sometimes they seemed unaware the rehabilitation team was planning admission to residential care, for example. Some seemed to have discussed rehabilitation goals with the team. However, most had limited awareness of the roles of various health professionals and perceived, when it came to discussing their rehabilitation goals, that "they never ask me" (P6).

...the group of doctors, I don't know what they, what they represent but they come and ask me a lot of questions (P2)

Theme 2: Create a hospitable environment

The experiences described by participants highlighted the importance of hospitality. Hospitality dominated the conversation, with much discussion about the staff, the physical environment, food, and practical matters such as parking or noise. To improve rehabilitation outcomes for people with cognitive impairment, an awareness of the importance of creating a safe and comfortable environment appears paramount.

All participants described the quality and attributes of staff. Staff were characterised as warm, lovely, kind, responsive, and hardworking with only the occasional person having "a sharp tongue" (P3). One support person said, "We sort of feel we've landed in paradise really, in terms of his care" (S4).

I can't find anything wrong anywhere. Ah, food's been wonderful, and nurses couldn't do enough for you, or the doctors. (P8)

...the staff is so nice, and you'll come into my room, and you say, "OK, meal's on" or "Dinner's on!" [in a sing-song voice] Naturally, I'll take notice of that. And I find most of the staff where I go have been lovely. (P3)

Personal connection with staff was also important, contributing to a sense of well-being while staying in the ward:

I think the name tags are really important for people who can see. Because there is that nice friendly feeling here, you do feel you can use a person's first name, even if you haven't been introduced to them. Just say it's a new nurse, her name is Jill – there it is. It's as if you're important ... not "important", but you're all on the same page, you're all on the same team. That's a really important feeling we've had here, isn't it. (S4)

The impact of their roommates was expressed as significant when patients described their sense of comfort and well-being while staying on the ward. Some mentioned feeling bored as they hadn't "struck up any friendships" (P1). Conflict was an issue for some, particularly around noise, the use of televisions, and the volume at which people spoke. Other interactions left patients feeling awkward or lacking in privacy:

I've got a lady in my room. And her chair's in my room. But we have never spoken to each other... She didn't say, but I'm sure she felt I was a real busybody, talking about everything and, "Do you like it in here? Have you been in before?" those sort of questions. And I think she thought, "What a busybody she is." So, I never ever did it again. I just waited for them to speak to me. Because not everyone wants to speak to who's in there with them. (P3)

We don't need to know these other people's stories. There's that little bit of a lack of privacy over the hearing thing. You get to hear all sorts of things, and you don't need it. You've got enough in your own head that you are trying to deal with. (S4)

Food quality, volume and palatability were described according to patient preferences. Some found it "monotonous ... and gristly" (S2), "too much" (P9) or "wonderful ... but they don't cook it enough for me" (P8). Others thought it was "pretty good" (P1) and appreciated alternative food options.

Other matters relating to hospitality were also mentioned. Parking was difficult to access, making visiting a challenge. The physical environment was described as “tired” (S2) and “depressing” with a need for brightness to help improve mood at a challenging time for patients (S6a). Some participants were grateful for the peace and quiet:

...up here it's so quiet. The girls have got all them soft shoes on and that. You don't hear nothing. Beautiful. (P8)

Theme 3: Recognise and work with care partners

The experiences described by participants acknowledged the role of family members as so much more than visitors. Family members were care partners, integral to the success of rehabilitation. To improve rehabilitation outcomes for people with cognitive impairment, recognising and working with care partners appears to be necessary.

The support provided by care partners was often described as longstanding and essential. There appeared to be some level of comfort for patients in knowing a family member could be an important source of information for staff:

[My daughter] knows just about everything I do and everything I would do and everything I wouldn't do. So, she can tell you. Yes, she'll tell you. (P3)

Impairments related to dementia, such as memory impairment or difficulty focusing during rehabilitation sessions, illustrated the need for care partners to be present, engaged, or kept informed by the rehabilitation team:

I come in in the afternoon, I said, “Oh, what did they say?” “I don't know.” He needs something in writing ... or something to communicate it to a family member, the closest family member maybe. Because he doesn't really recall it. (S2)

You can't just tell Dad. He can't remember, so it needs to come to the family. (S1)

Sometimes I do think they probably need a support person ... maybe if – maybe that we could come and support Mum with a bit of physio because we may be able to focus her. (S6a)

Despite emphasising the importance of care partners, participants described little engagement between staff and families. Some support persons were “not shy in coming forward” (P5) or received phone calls from staff, but others were either unsure of who to contact or found visiting hours “prohibitive” (S3):

There's nothing usually going on by the time I get here of an afternoon. There's nobody around. (S8)

Lack of communication, particularly regarding progress and discharge planning, was of great concern to support person participants. If patients were unable to remember discussions about discharge destination or timing, some support persons with responsibilities associated with their care were very keen to receive updates and, in some cases, experienced stress and anxiety:

...my biggest complaint is lack of communication with family. Been able to see senior nurses, but they've got a stock reply which tells you nothing. And erm yes, I've found that erm, very unhelpful. (S2)

I have been left pretty well stressed out of my mind, what would happen if [my husband] improved to a point where they wanted him not to be here, and he was sent home and I wasn't there. (S4)

Perhaps they did tell my sister ... when my name should actually be on the – I'm the, I guess, primary carer, but I haven't actually been rang. (S1)

Theme 4: Ensure staff have adequate dementia knowledge

The experiences described by participants relating to dementia-specific matters, such as the role of care partners, the need to understand the person, the impact of technology and the physical environment, and impairments in insight that may be present, drew attention to the importance of staff dementia knowledge. The importance of dementia knowledge underpinned all four themes generated in this study. To improve assessment of rehabilitation potential and subsequent outcomes, ensuring staff have adequate dementia knowledge appears to be essential.

The importance of staff dementia knowledge was highlighted by comments made by participants and comments *not* made by participants. For example, some participants were delighted with every aspect of care in the unit but appeared to be uninformed about the rehabilitation process and their own progress. They were sometimes unaware of having had significant injuries such as a fractured neck of femur. They appeared to have complete trust in the rehabilitation team, dependent on staff for advice and care and therefore dependent on staff holding appropriate knowledge and expertise:

I don't know. Just wait for them to tell me that I'm up to standard to be mobile and capable of moving about on me own. I'm still in the lap of the gods... I don't know whether I'm going to improve or not. You know, it's all just a mystery to me, is to how I'm going – whether I'm going to improve, or just be stuck in the same place. (P1)

I don't ever wonder how long I'm going to stay. I just come and I know that when I'm right to go home they'll send me. (P3)

They're the professionals and they're advising us how to get better. (S7)

Staff were described as dedicated and caring but lacking dementia knowledge. Patients were at times located far from the nurses' station, with the incorrect date on their whiteboard and with no ability to use the call bell if assistance was needed. The importance of understanding the person; their likes, dislikes, motivations, and desires was at times described as inadequate, and influencing patient care and outcomes:

My mother is losing weight ... nobody talked to me about her diet, and I don't think they talked to her. My mother hates custard, she got custard every night. (S3)

This lack of dementia knowledge was sometimes compensated for by family members with strong knowledge. However, this was only the case for some participants.

...Mum's fortunate because at least I know about memory impairment. What about all the families that don't and can't put things in place? I mean I got her a list of what she needed to do, I make sure that the date's right, but what about families that don't? (S3)

Discussion

The experiences described by participants in this study led to the development of four key themes that may inform improvements in access and rehabilitation outcomes for people living with dementia: support patients to engage in the rehabilitation process; create a hospitable environment; recognise and work with care partners; and ensure staff have adequate dementia knowledge. Our findings highlight the perspectives of people living with dementia and their family members. These perspectives have been reported in acute hospital studies [29] but are seldom heard in the rehabilitation literature. This study adds dementia-specific elements to findings from previous studies investigating the quality of rehabilitation for older people [13].

People living with dementia may require tailored support to engage in the rehabilitation process effectively, beyond what may be required for an individual without cognitive impairment. In our study, people with dementia or cognitive impairment had low knowledge of the rehabilitation process, which may have impacted their ability to participate effectively. The degree to which a patient participates in rehabilitation activities is a predictor of outcomes, particularly for people with cognitive impairment [30]. An inability to participate in rehabilitation is often cited in clinical practice as the reason a person with dementia may have poor rehabilitation outcomes, or why someone may not be provided an opportunity to be admitted to a rehabilitation unit [6]. However, there are specialised approaches needed to promote and support participation for people with cognitive impairment. Finding ways to improve a person's ability to participate in rehabilitation is essential. For example, findings from a scoping review on the quality of geriatric rehabilitation from the perspective of patients, including only one patient with dementia, suggested patients need more information about the rehabilitation process [13]. Our findings suggest that more is required for people with dementia or cognitive impairment. Information may be helpful, but how this information is presented requires careful consideration by clinicians. For example, people with dementia may benefit from using memory aids such as books or charts [31], or greater family involvement [16,32].

Involving family as care partners can be challenging in the inpatient rehabilitation environment but may be essential for some people living with dementia. Our findings suggest care partners are often longstanding sources of support, and a vital information source for health professionals. They can help a patient focus in therapy sessions and contribute to discharge planning if a patient has insight or memory impairments. Previous literature supports these results. In geriatric rehabilitation, the importance of families as a source of social contact, mental support, and help with practical tasks has been emphasised [13]. Training families to assist with activities such as supervised walking increased physical activity levels for older people in transitional care, and supported goal attainment and adherence to the advice of health professionals [33]. However, our findings from the perspectives of people with dementia and their families, support descriptive research about dementia-friendly hospitals arguing that families are often care partners, more than visitors, and should be welcome at any time, even able to stay overnight if needed [34]. Despite the importance placed on the role of care partners, our findings also indicated limited communication from health professionals and some challenges navigating visiting hours. This has been significant during the coronavirus pandemic but is also relevant to closing aged care wards in times of flu or other disease outbreaks. Clinicians and hospital administrators could consider whether changes to the cultural or physical environment might support more intentional involvement of care partners in geriatric rehabilitation units.

The participants in our study placed deep value on hospitality, particularly the kindness of staff. This finding is similar to the need for socialising, and fostering meaningful relationships with staff, identified in a study in the acute hospital setting [29]. Other topics relevant to hospitality included the impacts of food quality and choice, parking, noise, and relationships with other patients. Health professionals and patients often have different perspectives about contributors to quality care [13]. Matters such as the impact of other patients can be of high importance to patients [35] but may be underestimated by staff. The impact of environments cannot be understated for people living with dementia. Although people with dementia are often labelled as displaying “behaviours of concern” in hospital settings, it is highly probable hospitals,

including rehabilitation units, are “environments of concern” for some patients [36]. Careful consideration of environmental matters for people with dementia, incorporating the views of what people with dementia and their families believe is essential in creating a hospitable environment, may help support better rehabilitation outcomes.

Underpinning all themes generated in this study was the foundational importance of staff dementia knowledge. Suboptimal dementia knowledge amongst health professionals has been identified in previous research using objective measurement tools such as the Dementia Knowledge Assessment Scale [37,38]. To the best of our knowledge, the importance of dementia knowledge in inpatient geriatric rehabilitation environments has not been captured by listening to the perspectives of people living with dementia and their support people. Without a detailed understanding of dementia, staff may miss critical information vital to patient care. For example, asking a patient about their needs or wants may be considered person-centred. Yet if a person lacks insight into their condition – in our study, one patient was unaware they were recovering from a hip fracture – they may miss the care they need, such as receiving timely analgesia. Speaking directly with patients is respectful and needed. Still, a staff member with dementia knowledge may also consider discussing a plan for regular analgesia with a patient with cognitive impairment and include their care partner in the conversation. Staff with knowledge about dementia will also understand non-pharmacological approaches to behavioural and psychological symptoms of dementia and be alert to sudden-onset cognitive symptoms that may indicate delirium [37]. They will be mindful of the importance of continuity of care, the need for person-centred care, the value care partners bring, and will understand and respond to the impact of the environment [34]. Health professionals' dementia knowledge is a global issue, but there are various groups making incremental changes through the development of education programmes such as the Dementia Champions programme in Scotland [39] and the Dementia Care in Hospitals programme in Australia [40].

A strength of this study was the inclusion of the views of people with dementia and cognitive impairment. Although these views may have been impacted by cognitive impairment, they represented reality for each participant during the interview. Including the perspectives of patients and support people in the same analysis may be a limitation. Indeed, the perspectives of patients and support people were different at times. However, this highlights one of our findings, that family members are often care partners and contribute important insights in a clinical setting. We could not include people with severe cognitive impairment in this study due to laws about consent, so only present findings relevant to people with mild to moderate impairment. A limitation of this study is the inclusion of a small number of participants from one rehabilitation unit. Although there was adequate information power to answer our research questions [41], a broader range of participants may have led to the development of different or additional themes. Nevertheless, our findings were congruent with relevant literature in the field.

Readers should take note that our second research question – how can inpatient rehabilitation units improve rehabilitation access and outcomes for people with dementia – is not answered in objective terms and is not based simply on the response of participants to a question about what could be better. Guided by interpretive description methodology, experiences described by participants were interpreted through a clinical lens brought to the analysis by the research team, resulting in the reported themes. Future research could investigate the implementation of our findings into clinical

practice to see if they influence objective rehabilitation outcomes, and clinicians and health service administrators could consider how to address each theme in their own context.

Conclusion

This study sought to understand the views of people living with dementia and cognitive impairment who were participating in rehabilitation, and the opinions of their families. Our findings complement studies conducted in the acute hospital setting and add to the rehabilitation literature that has not previously included the views of people with cognitive impairment. Themes about engagement in the rehabilitation process, hospitable environments, care partner acknowledgement and dementia knowledge give clinicians and hospital administrators key points to consider when endeavouring to improve quality of care, and rehabilitation access and outcomes for people living with dementia.

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The authors report there are no competing interests to declare.

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Data availability statement

The authors confirm that the data supporting the findings of this study are available within the article and its [supplementary materials](#). Due to the nature of research, more detailed data are not available for ethical reasons.

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