PALLIATIVE MEDICINE

Original Article

Palliative Medicine
2021, Vol. 35(6) 1148–1157

DOI: 10.1177/02692163211013250
journals.sagepub.com/home/pmj
SAGE

‘Traversing difficult terrain’. Advance care planning in residential aged care through multidisciplinary case conferences: A qualitative interview study exploring the experiences of families, staff and health professionals

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Abstract

Background: Advance care planning improves the quality of end-of-life care for older persons in residential aged care; however, its uptake is low. Case conferencing facilitates advance care planning.

Aim: To explore the experience of participating in advance care planning discussions facilitated through multidisciplinary case conferences from the perspectives of families, staff and health professionals.

Design: A qualitative study (February–July 2019) using semi-structured interviews.

Setting: Two residential aged care facilities in one Australian rural town.

Participants: Fifteen informants [family ($n = 4$), staff ($n = 5$), health professionals ($n = 6$)] who had participated in advance care planning discussions facilitated through multidisciplinary case conferences.

Results: Advance care planning was like navigating an emotional landscape while facing the looming loss of a loved one. This emotional burden was exacerbated for substitute decision-makers, but made easier if the resident had capacity to be involved or had previously made their wishes clearly known. The ‘conversation’ was not a simple task, and required preparation time. Multidisciplinary case conferences facilitated informed decision-making and shared responsibility. Opportunity to consider all care options provided families with clarity, control and a sense of comfort. This enabled multiple stakeholders to bond and connect around the resident.

Conclusion: While advance care planning is an important element of high quality care it involves significant emotional labour and burden for families, care staff and health professionals. It is not a simple administrative task to be completed, but a process that requires time and space for reflection and consensus-building to support well-considered decisions. Multidisciplinary case conferences support this process.

Keywords

Advance care planning, case conferencing, nursing homes, end-of-life care, rural, qualitative methods, multidisciplinary communication

What is already known about the topic?

- Advance care planning improves the quality of end-of-life care for older persons in residential aged care.
- The uptake of advance care planning is poor, and possibly lower in rural settings.
- A systematic approach, such as case conferencing, facilitates advance care planning.

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What this paper adds?

- Advance care planning is a significant emotional labour and burden for families, care staff and health professionals.
- There is no 'one size fits all' approach, and family members may not feel 'ready' despite participating in the planning process.
- Multidisciplinary case conferences facilitate informed decision-making, coherence and shared responsibility in rural residential aged care settings.

Implications for practice, theory or policy

- Effective advance care planning requires space and time for preparation, reflection and consensus building.
- Families appreciate the opportunity to consider all options to make informed decisions.
- The ideal approach enables participants to be 'all on one page' while 'no one size fits all'.
- Multidisciplinary case conferences can support this process.

Introduction

Advance care planning is the process of discussing and recording a person's values, beliefs and preferences to guide future decision-making in the event of decision-making capacity being lost.[1,2] Advance care planning is a priority for quality person-centred palliative or end-of-life care to ensure treatment and care is consistent with a person's values, goals and preferences.[3,4] While the practice and legal framework of advance care planning differ between countries and jurisdictions, ideally it involves a conversation with a person's family or other significant person and relevant healthcare professionals and leads to a written advance care plan. An advance care plan can be informal (e.g. a letter to the person responsible for the decision-making or an entry in a medical report) or a formal legal document such as an advance care directive.[2] Whatever the format, it is imperative that the written plan fully reflects the person's wishes and is sufficiently informative to guide clinical decisions.[5]

Advance care planning in residential aged care (also known as nursing homes), has been shown to have positive benefits for both residents and their families.[6,7] These end-of-life care plans ideally include anticipatory treatment orders for end-of-life medications, 'do not resuscitate' and 'do not hospitalise' orders. Advance care planning has been reported to reduce unnecessary transfers to hospital, decrease a person's anxiety about the future, help families to prepare for death by improving their understanding of a person's wishes, and increase the number of residents dying in their home (residential aged care) and the chance of medical treatments being consistent with a person's wishes.[6,8,9] Despite the many benefits, uptake is poor,[1,10] possibly due to a lack of awareness and understanding, or a general reluctance to have end-of-life conversations.[3] Compared to urban settings, the uptake in rural areas is thought to be lower due to limited resources and training.[11,12]

In residential aged care settings, advance care planning faces additional challenges. An estimated 50% to 80% of residents are living with some degree of dementia[6] and associated impairment or loss of decision-making capacity. The responsibility for advance care planning often falls on a substitute decision-maker (family member or guardian), especially if advance care plans are outdated or non-existent.[13,14] In rural settings, the lower uptake of advance care planning is significant. Compared to their urban counterparts, substitute decision-makers in rural locations have a greater acceptance of death as a natural part of life and are therefore less likely to want life prolonging interventions.[15,16]

The Australian Royal Commission into Aged Care Quality and Safety recently acknowledged that residential aged care providers play an important role in the uptake and implementation of advance care planning, and that better education of healthcare professionals and staff could improve utilisation.[3] As in other countries, advance care planning is a Quality Standards requirement in all Australian residential aged care facilities.[17,18]

High-quality advance care plans reflect high-quality planning processes.[5] Case conferencing is one evidence-based approach that facilitates advance care planning.[19] International studies within residential aged care settings have shown that multidisciplinary case conferences with family members improve communication and interpretation of information, and have educational value.[20,21] Onsite, case-based educational potential is particularly important in rural settings as access to education, training and mentoring is often limited.[22]

There is a paucity of studies reporting the experience of substitute decision-makers (families) and healthcare professionals participating in end-of-life care planning discussions within multidisciplinary case conferences in rural residential aged care. Much of the advance care planning literature reports prevalence, timing, approach, content, outcomes or hypothetical perspectives. Following the consolidated criteria for reporting qualitative research (COREQ) guidelines,[23] this paper reports results of a qualitative investigation which aimed to explore the experience of advance care planning discussions facilitated through multidisciplinary educational case conferences, from the perspective of rural care staff, families and external healthcare professionals, including general practitioners (GPs). For the purpose of this study, advance care planning refers to anticipatory end-of-life care planning for residents with a life expectancy of 12 months or less.

Methods

Research question

This study addressed the question: What are the perceptions of rural residential aged care staff, residents, families and other health care professionals relating to anticipatory end-of-life care planning discussions facilitated through multidisciplinary case conferences?

Design

This was a nested, descriptive qualitative interview study, undertaken between November 2018 and July 2019. This study formed part of a convergent mixed methods hybrid implementation-effectiveness study[24] that evaluated a multidisciplinary educational case conference intervention to support advance care planning reported elsewhere.[25]

Setting

This study was conducted in two residential aged care facilities in a rural town of approximately 6680 inhabitants in south-eastern New South Wales, Australia. Both sites are not-for-profit, with a total of 112 resident places (72 and 40, respectively). Primary palliative care is provided by facility staff and GPs with support from a community-based palliative care clinical nurse specialist. A private part-time palliative medicine physician (SR) is available for residents with complex palliative care needs requiring additional medical expertise. Prior to the study, GPs rarely attended informal facility-led family case conferences, preferring to communicate independently with residents and families.

Intervention – Advance care planning through multidisciplinary educational case conferences

Multidisciplinary educational case conferences (hereafter case conferences) were implemented to facilitate end-of-life care planning for residents. A multidisciplinary approach was utilised to replace existing 'silo' approaches. Case-based discussions were employed to provide educational opportunities for all attendees, potentially increasing the capacity of staff to care for residents at end of life. Case conferences were structured 1-h meetings attended by residents (where appropriate), family members (or other substitute decision-maker) and a cross-section of care staff and health care providers (including the GP, a community pharmacist, palliative medicine specialist and community palliative care nurse). Case conference discussions focused on the resident's current care needs and prognosis, and planning for end of life including goals of care, preferred place of care and death and medications (deprescribing and anticipatory prescribing).[25] Residents without a clear or up-to-date advance care plan were identified by senior care staff and GPs for a case conference. Priority was given to those residents who had a recent (3 months or less) significant deterioration or hospitalisation. Case conferences were scheduled monthly; however, flexibility in scheduling allowed for urgent case conferences to be convened at short notice. After obtaining informed consent from the resident and/or their guardian, facilities organised and co-ordinated a face-to-face case conference at the facility, led by a palliative medicine physician (SR). A Residential Medication Management Review[26] was completed by the community pharmacist prior to the case conference. For consistency, the Palliative Approach Toolkit case conference summary sheet guided the agenda.[27] Outcomes were documented by the attending registered nurse. If agreement was reached, the GP and resident or substitute decision-maker signed the completed end-of-life care plan.

Ten case conferences were convened. In total, five residents (an additional five residents with severe dementia did not attend), 16 family members, 17 facility staff, five GPs, a community pharmacist and three community palliative care nurses attended at least one case conference.

Interview participants

To obtain a broad range of views and experiences, our protocol included a convenience sample of residents, families, staff and other health care professionals. Inclusion criteria included participation in at least one case conference, 18 years or older, English speaking, and capacity to provide consent.

Interview recruitment

All attendees ($N = 47$) from ten case conferences were invited to participate in one-off, face-to-face interviews. Interview invitations were included in a written evaluation survey handed to all participants at the end of each case conference. Those willing to be interviewed provided their contact details on returned surveys, after which they were sent a participant information sheet and written consent form. Prior to each interview, consent was re-confirmed by SHD.

Data collection

Semi-structured interviews, lasting between 14 and 51 min (mean 36 mins), were conducted with 15 participants at mutually convenient locations (workplaces and private homes) between February and July 2019, by SHD. The interviewer, a registered nurse and experienced qualitative and mixed-methods researcher was unknown to participants prior to the study (six interviewees met SHD prior to the interviews through her role as research observer of the case conference advisory group meetings).[25]

Family interviews were conducted between 4 and 8 weeks after participating in a case conference; staff and healthcare professional interviews were between 10 and 193 days (mean 68 days) from their most recent case conference. Question prompts, stratified for interviewee role, related to interviewees' experience of advance care planning and case conference participation can be found in Supplemental File 1. Interviews were audio-recorded and professionally transcribed. Active listening was utilised to confirm correct understanding; transcripts were not returned.

Data analysis

Data were analysed inductively by SHD, SR and a research assistant (RK). Data were coded in NVivo11 (QSR International, 2015) and analysed thematically using the approach of Braun and Clarke (data familiarisation, generating initial codes, searching for themes, reviewing themes, defining and naming themes).[28] Coding employed both a deductive framework oriented towards the overarching aims of the implementation-effectiveness study that focused on the acceptability, effectiveness, enablers and barriers to case conferences; but also coded inductively for nascent concepts. Following completion of interviews and initial reading of transcripts, a preliminary coding tree was developed by SHD and SR. Open and axial coding were subsequently undertaken by RK and SHD to identify, refine and synthesise emergent categories and themes. The interview sample was bounded by time constraints for the study and, while data were rich and comprehensive, it is not certain that thematic saturation was reached.

Ethics

This study was approved by the Australian National University Human Research Ethics Committee – protocol 2017/933, variation (2) dated 29/10/2018. To avoid 'gate-keeping' of vulnerable and frail residents by family and staff, residents with cognitive capacity were invited to attend their case conference and to participate in an interview.[29] Written informed consent was obtained from all interviewees. The lead investigator (SR; a clinician and qualitative researcher) was well known to all participants.

Table 1. Interview participants.

	N (%)
Gender	
Male	3 (20.0)
Female	12 (80.0)
Role	
Family member # ¥	4 (26.7)
General practitioner	3 (20.0)
Registered nurse*	5 (33.3)
Community pharmacist	1 (6.7)
Residential aged care assistant	2 (13.3)
Residential aged care facility	
Site 1	7 (46.7)
Site 2	2 (13.3)
External (GPs and community staff)	6 (40.0)

#: 3 related to a resident with dementia, 1 related to resident with full capacity who attended her multidisciplinary case conference; ¥: family members – 1 husband, 3 daughters.
*Registered nurses – 3 residential aged care facility nurses, 2 community palliative care nurses.

To minimise potential response bias within the interviews, an external interviewer (SHD) was appointed. Anonymity of interview participants was maintained by assigning a code to each participant.

Results

Fifteen case conference participants were interviewed (response rate 30%). Participant characteristics are detailed in Table 1; no residents agreed to interview.

Four key themes were identified (see Table 2). Two of these ('how the project works' and 'thinking beyond the project') are evaluative and are reported elsewhere.[25] Two experiential themes: 'traversing difficult terrain' and 'impact of case conferencing on advance care planning' are presented here.

Traversing difficult terrain

In this study, case conferences intersected with a 'difficult journey' that residents and families were making, to deliver specific support for end-of-life care.

Navigating the emotional landscape

While the underlying context was often described as a 'journey', a key concept in these descriptions was the awful nature of the terrain and the looming loss waiting at the end: 'it's a horrible, horrible place to be' [F09, family]. This was a deeply personal and emotional landscape, littered with areas of pain, that must be navigated:

> *I think the reason for the case conference was that we had hit the palliative care stage. So it wasn't like we were planning*

Table 2. Interview themes and sub-themes.

Meta-themes	Themes	Subthemes
1. How the project works (implementation)	Program logic and strategy	Advance care plans
		Anticipatory prescribing
		Case conferences
		Information custody and documentation
	Enablers and success factors	Goodwill
		Participants
		Preparation
		Skills, roles and competencies
		Timing
	Challenges and barriers	Multidisciplinary case conference
		Anticipatory prescribing
		Advance care plan
2. Traversing difficult terrain	Navigating the emotional landscape	Emotional burden
		Moving towards loss
	Having 'the conversation'	An open conversation
		Things that are difficult to say
		Preparedness
		Timing and space
3. Impact of case conferencing on advance care planning	Differential effects	
	Education and awareness	Informed decision-making
	Connection and coherence	Being on the same page
		Comfort and support
		Connecting around the patient
	Clarity and focus	Clear understanding
		Informed decision-making
		Structure and visibility
4. Thinking beyond the project	Scalability/transferability	
	Sustainability	

> *Mum's longer term care, it was that she had effectively hit that next stage. . ..I think I've known all along what to expect. I think it's not about what to expect, it's about how you get there.* [F09, family]

For family members, especially those required to make decisions for cognitively impaired relatives, this was a particularly emotional burden, often compounded by the distress of other decisions or responsibilities such as placing loved ones into care:

> *Yes, I found it hard to put her in [to residential care]. . ..It's one of the hardest things I've ever done. It broke my heart.* [F07, family]

In the case of one resident, who participated fully in her case conference, this burden was somewhat ameliorated for her family by the knowledge that she was able to communicate her wishes and was comfortable with the decisions made:

> *I think it was because of that whole conversation that Mum felt she could actually go. That it was sorted . . . .. . Because there had been a number of things in Mum's life where people had argued over things before and after a death. And it was the last thing she wanted . . ..she had been able to say, "This is what I want. Yes, you've asked me, and now I'm telling you. And I'd like you to do it."* [F08, family]

Staff and GPs indicated that the end-of-life care discussions were an emotional burden for them as well. They reported long established relationships with some residents that added pressure to their decision-making responsibilities while watching residents deteriorate or suffer:

> *The first [dying resident] that I started to see, I was pretty close to. You get really close to them. He had a fall, hit his head and he had a stroke. And the way I could handle it - not knowing when he was going to [die] - I wanted to know how his blood pressure was and all that.* [S15, care assistant]

Having 'the conversation'

Participants reported that end-of-life conversations were difficult to have, and to initiate. Some staff reported discomfort with opening these discussions with families or felt they did not have the skills to do this competently:

> *Some of the younger [staff], they're not as used to talking to people about end of life. It's difficult for some people and it depends also on their history of themselves and what their families are, what's happened within their own families. Some people are not as good at talking on end of life.* [S14, registered nurse]

Participants reported that often 'the conversation' was not one that could be neatly commenced and completed inside an allocated meeting slot but took place over time and required space for reflection. Substantial preparation and backgrounding were needed for residents or substitute decision-makers to be ready to participate in, and able to contribute to, this ongoing discussion:

> *Well, the last case conference that we had, I guess I spoke to his son about three times and he asked me different questions each time. . .So with leading questions, I could finally get him to understand what he wanted to ask.* [S22, registered nurse]

Participants reported that some families, especially when residents were unable to make their own decisions or there were conflicting opinions among family members, required space and time for reflection and consensus building. Even within coherent family groups, individuals had different levels of understanding, familiarity and readiness for the choices which needed to be faced:

> *Again, the three of us, we didn't know the aged care system, we don't know that system at all until you are in it, until – and then the three of us looking at each other with a blank look going, "What do you think? What do you think? Do you reckon she'd take it? How do we da-da-da-da-da?" And then having that sort of family discussion in front of everybody else was something I think we could have been a bit more prepared for.* [F09, family]

Despite advance care plans being established and accepted, readiness to action the plans often remained a fluid and burdensome concept, as illustrated by one family member:

> *One time before she went into care she collapsed in the garage, and I had to ring 000. She didn't become unconscious. She was still breathing, and I was thinking, even though I had the care plan, I thought, this is too sudden and I'm on my own. And so I thought, if they told me to do CPR, I probably would do it. And when I got down to the hospital, the doctor said to me, you don't want to revive her, do you? And when that reality hits you, it's different to writing it down. When it's staring you in the face, it's very confronting. . . I thought gee, the reality is so different to the theory . . .and you say 'no', but oh, it's heart wrenching.* [F07, family]

Impact of case conferencing on advance care planning

Differentiated effects. Participants identified benefits resulting from case conferencing; however, end-of-life care planning and the experiences that surround it were perceived as an emotive and taxing journey rather than a simple task to be completed. Participants acknowledged that individuals have different needs and perspectives and 'no one size fits all' [F09, family]:

> *I was interested to hear what some of the palliative care people had to say. I don't know that my sister and my father were ready to hear that, but I think that's just because as a family we're grieving, and we're grieving at different stages. And anyone who's in that space, there are some things you take on board and some things you don't. And that's just going to be – yeah, I think I'm in a different place than my sister and we're both in a very different place to our father.* [F09, family]

Education and awareness. Almost all respondents agreed that the case conferences had educational value, although this operated in different ways for different people. Educational value for care assistants was often about grasping the range of perspectives and logic for medical management decisions:

> *It was good because in that situation [when medications were changed], you could say, "OK so why?" – even though we don't really need to know the information, because we don't pass it on to residents, it sort of makes you feel like oh yeah, right, this is why they're doing this.* [S18, care assistant]

The emphasis for health professionals was on two-way learning within the multidisciplinary team:

> *It's good to be discussing things face-to-face with the patient and the doctor, because in being a pharmacist, I don't really have a lot of time with the patient and their family. So it's good to see things from their perspective as well. . .I think it works both ways. I'm learning a lot from [the specialist], in terms of the palliative care side of things, a lot. And I hope that, you know, they will get something out of a pharmacist being involved as well.* [S01, pharmacist]

For families, the educational value of case conferencing was in developing a more consolidated understanding and awareness of likely prognostic trajectories and feasible treatment options:

> *Well, they were able to explain a little bit about the different options.* [F03, family]

Participants reported that differentiated detail about alternatives enabled residents and families to make more informed and comprehensive decisions which could be implemented with greater specificity. This, in turn, enabled care staff to enact treatment choices that were explicitly formulated and communicated:

> *I think they've got more guidelines on what the person wants, because it has been discussed. So hopefully, if something*

> *happened and they rang the family, they could say 'look, as you know, it was all discussed and we've got it written down as to what Joe Blow wanted'. And that will help the family rather than a panic, 'oh gosh, should they go to hospital?' It doesn't eliminate that totally, but if you can say 'remember, that was discussed at the meeting', you've got something to fall back on.* [S05, registered nurse]

Connection and coherence. Participants described case conference discussions as enabling families and staff to 'get on the same page', [F03, F09, S14, S18] facilitating coherence and alignment around outcomes as well as the perspectives and wishes of multiple parties:

> *It gave a chance for everybody involved to hear what the doctor had to say, hear what the family had to say, hear what the carers had to say. . .. . the doctor got the opportunity to say what they thought was going to happen and you could see whether the family was understanding what the doctor was saying. And they got their chance to talk. So you get a perspective of what everybody is thinking, not 'I wonder if this is what they want'? sort of thing.* [S18, care assistant]

For care assistants, this was especially important because they are intimately involved in the daily care of residents:

> *I mean it happens all the time, families talk to management and RNs and that sort of thing, we get a small amount of feedback but we don't actually hear it from the mouths of the people that are really involved in it.* [S18, care assistant]

Comfort was important to residents as they made decisions about end-of-life care. Comfort also emerged as an outcome for families as they proceeded with the 'journey'. For families and staff, transparency and knowing who was party to that agreement, as well as having a sense that options had been fully considered and explored, provided comfort and a degree of certainty in the face of impending loss:

> *But it's that degree of comfort. And I think it's because everyone knows we actually want the same thing, which is her to not be in pain, to be comfortable, and to go peacefully. [And] that they're comfortable enough to talk about it.* [F03, family]

Comfort enabled families, care assistants, nursing and medical staff to approach the next steps with calm resolution and to connect and bond around the resident in a way that focused on their wishes, even across setting transitions (see vignette, Box 1). One family member suggested that after the case conference care staff felt 'confident in knowing what they're doing is consistent with what we all wanted' translating to a 'better level of attention' to the resident's needs [F03, family]:

Box 1. Vignette illustrating the value of advance care planning in empowering clinical responses across care transitions.

Mum had a chest infection and the nurse rang and said, 'I think she might need to go off to hospital for some oxygen and some antibiotics' . . . having had the conference, that was what she had said she was prepared to do, but not for too long. . .. My sister was not keen on this arrangement. . . but I just said to her, 'these are Mum's choices, and that's what's happening'. [A few days later] Mum told the [hospital] nurse at about 2 am that she'd had enough of all of this stuff [IV antibiotics], and she wanted it all gone. The nurse was quite convinced that Mum knew exactly what she was doing and saying. This was a point in her life that she had reached, and she had the right to say. So [the nurse] said 'sure, the notes tell me that's what your wishes are. . .I'll take these things away, but I'm going to ring your daughters because they'll want to come and make sure you're comfortable'. And she was just very comfortable and drowsy and we just sat with her. [Two days later] she was gone. . .it was perfect, it was everything she wanted. [F08, family]

> *As an example, one of the staff felt like they wanted to do something extra for Mum, so they brought up a food processor, and have been making her smoothies, when they're on shift. So they make. . .. banana smoothies, and in her handover, tells the other staff that there are smoothies made in the fridge for Mum. And that, to me, is quite exceptional. Now what triggered that? Can't say for sure, but there seems to be a lot more of that now.* [F03, family]

Some staff felt case conferences provided a mechanism for resolving tensions by articulating issues that would otherwise be difficult to broach. Staff reported observing changes in the confidence of families to rely on care staff:

> *I think they feel very free to discuss with us what's going on with her care. . .. . ..I think before, particularly the husband's realisation of her degree of dementia, sort of in a way clouded where he was coming from. He's always been very, very caring of his wife. But sometimes over caring in a way that isn't letting go, to let the staff help with the physical so much. And he's actually looking after himself a bit better by having a bit more time away, trusting us. There's a big trust there now, I think, which is really good. Because he knows we're open with him.* [S14, registered nurse]

Clarity and focus. Participants reported that case conferences provided clarity on the current situation. One family member (F09) described this as being 'aware' rather than 'prepared'. The mutual exchange of information during case conferencing enabled people to both make their position clear, and be clear about their understanding of others. This was characterised by a GP participant as 'just listening and understanding' [S17, GP].

> *I think it was really useful to have a mixture of people in the room, like the GP and pharmacist and carers, because there were some elements that I wasn't as aware of around Mum and her, how she's been living and coping, until all of those people were in the room. Equally, a number of staff after the case conference told me that they found it really useful because they were also exposed to information that they didn't have before, and it helped them understand some things a bit better in terms of Mum's care*. [F03, family]

For families, clarifying their understanding of what the journey might hold, what the options are, what is feasible and achievable, was confronting yet offered a sense of control. The technique of drawing specific, detailed distinctions between decision points and treatment options, such as the use of intravenous fluids or antibiotics, added to perceived clarity and gave residents a way to be explicit about their wishes:

> *So it gave me clarity about what would be the last stages and where she would be. So that was good.* [F07, family]

Increased clarity strengthened informed decision-making by residents and empowered families to represent relatives' wishes with authority and self-assurance:

> *Just having that control, from my perspective anyway, was really important, because it meant that I could say with some authority, "Mum doesn't want this. Don't do this. Or Mum will have that". And my daughter was with us on the Sunday night, and she said "Mum, is this what Nonna wants?" And I said "Nonna said, antibiotics yes", while ever they're effective. But if it looks like they're not going to be helpful, no, she doesn't want them. Oh.* [F08, family member]

Discussion

Main findings

This paper reports the experience of participating in advance care planning, facilitated through multidisciplinary end-of-life case conferences, from the perspectives of residential aged care staff, families and external healthcare professionals in one rural town. Consistent with previous research,[30] participants reported multidisciplinary discussions to be beneficial. However, they also likened the advance care planning process to traversing difficult terrain as they made decisions while facing the looming loss of a relative or friend. This emotional burden[31] was exacerbated for substitute decision-makers of cognitively impaired residents; but made easier if the resident had capacity to be involved in the discussion or had previously made their wishes clearly known. Having 'the conversation' was not a simple administrative tick-box task but required space and time in which to prepare and to come to terms with decisions. Multidisciplinary case conferences were educational and facilitated informed decision-making and shared responsibility.[32] Knowing that all care options had been considered provided families with clarity, control and a sense of comfort. This enabled all stakeholders to bond and connect around the resident to help facilitate a 'safe death'.[33]

Strengths and weaknesses

A broad perspective is provided by the inclusion of family members, and a cross-section of facility staff and health professionals who had recent firsthand experience in end-of-life care planning discussions through the case conference approach. Family members included both substitute decision-makers and those supporting a family member with full decision-making capacity. Residents with decision-making capacity participated in the advance care planning discussions; however, none volunteered to be interviewed and therefore their personal voice is unheard in this paper. Interviewees were self-selected and while this had the potential to skew the data, interviewees offered both positive and negative feedback on the end-of-life care planning approach. The study was conducted within fixed timeframes. While the data collected were rich, and themes began to be repeated as analysis progressed, due to the small numbers within each participant category, thematic saturation was not conclusive. Whether the experiences reported would be similar or different in non-rural (or other rural) sites is beyond the remit of this study.

What this study adds

One suggestion for the low uptake of advance care planning in residential aged care is the unwillingness of people to engage in end-of-life discussions.[3] However, in this and previous studies, residents (when appropriate) and families were willing to participate in advance care planning discussions despite finding them challenging.[30,34]

Advance care planning is not a simple process and may require repeated conversations.[31] The use of passive informative material on its own is often not sufficient; facilitated, interactive, informative interventions are more effective.[8,14,35] Most families in this study appreciated the sharing of the decision-making responsibility facilitated by the case conference in providing families with an opportunity to engage in the discussion, to ask questions and to hear perspectives from a cross-section of health professions.[13]

This study indicates that the process of advance care planning is not the same for everyone, even within family units and a one size fits all approach is unlikely to be ideal. While some residents and families were pragmatic in their approach, others required space and time to come to terms with looming end of life.[30] Since family carers of people with dementia have often taken on the role of substitute decision-maker throughout the course of their relative's dementia,[13] one might be mistaken in believing they would be proficient in making difficult end-of-life decisions. As illustrated by some participants in our study, not all family members have accepted that dementia is a terminal illness or, due to the slow trajectory,[36] may not recognise that their family member is deteriorating. End-of-life discussions are confronting and emotionally difficult and participants may be uncertain in making end-of-life treatment decisions.[31,37] Even when planning is well established and supported, substitute decision-makers may not feel 'ready' or well prepared for the consequences.

This paper addresses the paucity of papers reporting the collective perspectives of families, residential aged care staff and health professionals who actively participate in end-of-life care planning discussions. The paper potentially adds some rural perspectives on advance care planning in residential aged care through multidisciplinary case conferencing. However, while aged care residents, staff and GPs in this study were local rural residents, participating families were from both local and distant (including urban) locations. As a result, the perspectives provided, and issues (positive and negative) raised are not specific to the rural setting and it is not possible to determine uniquely rural concerns in this study. This approach to advance care planning could be applied to any setting.

Conclusion

Advance care planning is often an emotive and taxing journey, especially at end of life. The emotional burden can be eased by allowing families, especially substitute decision-makers, space and time for reflection and consensus building to enable informed and well-considered decisions. Multidisciplinary case conferences can support the process of advance care planning through shared decision-making responsibility. This leads to a sense of connection and coherence around the resident, which can offer comfort to many stakeholders including relatives, care staff and health professionals.

Author contributions

SR, SHD, CP and NG made a substantial contribution to the study design. SR was the chief investigator for the study being responsible for study administration and management. SHD conducted the interviews. SHD, RK and SR analysed the qualitative data. SR wrote the draft paper; all authors revised it critically for important intellectual content. All authors read and approved the final manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project was supported by funding from COORDINARE – South Eastern New South Wales Primary Health Network through the Australian Government's Primary Health Network Program. The funder had no role in the conduct of the study or interpretation of the results.

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Data availability statement

Data are available to bona fide researchers by contacting the corresponding author.

Supplemental material

Supplemental material for this article is available online.

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