

Palliative care delivery in residential aged care: Bereaved family member experiences of the Supportive Hospice Aged Residential Exchange (SHARE) intervention

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Abstract

Background

The supportive hospice aged residential Exchange (SHARE) is a new model of palliative care education that has been designed for residential aged care. The goal of SHARE is to help clinical staff improve palliative care within residential aged care facilities and to improve specialist palliative care nurses' knowledge and skill to care for frail older people.

Method

The experiences of 16 bereaved families concerning the palliative care journey (both at the start and finish of a one-year implementation of SHARE) were explored using semi-structured interviews.

Results

Four themes were important to bereaved families' experience: communication with staff, relationship with general practitioners, systems of care, and hospice involvement. A sub-theme indicating changes in these four components of care between the start and finish of SHARE was identified. A fifth theme highlighted challenges (staff shortages and turnover).

Conclusion

Findings indicated that SHARE benefited families (improved communication and support) through the end of life journey of their relatives, but challenges remained.

Background

New Zealand, like many developed countries, has an ageing population. By 2035, it is expected that almost 25% of New Zealand's population will be over the age of 65 (1). Increasing age often includes multi-morbidity and frailty and an increasing need for more comprehensive and complex care, especially at the end of life (2). From 2003–2007, 38% of deaths in New Zealanders aged over 65 were in residential aged care (RAC) facilities (3). In New Zealand (Aotearoa), the term RAC covers a range of long-term aged care services, based on level and type of care need including: 24-hour hospital care, rest home care, and dementia/psychogeriatric care (4). The RAC ownership model within New Zealand is predominated by large privately owned facilities.(3) At the end of 2019, New Zealand had 39,000 residential aged care beds(1). This number is only expected to increase, with an estimated 52,000 RAC beds being required by the end of the decade (1). Overall, if current patterns continue, the majority of deaths for people over the age of 85 will be in RAC, accompanied by increased complex geriatric, frailty and multi-morbidity care requirements being more complex as time progresses (5, 6). As a result, there is a growing burden for New Zealand RAC facilities to provide good quality palliative and end of life care (7).

Palliative care is defined as care for a person with a life-limiting illness that aims to optimise the quality of life for the person, as well as support their whānau (family) caregivers both during illness and after death (2). Palliative care is one component of an overall health care plan and may be more needed than a purely treatment focused plan at the end-of-life care (8). Palliative care is delivered by both generalists as a part of standard clinical practice by any healthcare professional and by specialist palliative care professionals who have undergone specialist training in palliative care (2). Hospice provide both in- and out-patient, palliative care for those with a terminal or life-limiting diagnosis (9). However, for many older adults in RAC, palliative care will be required for a chronic non-malignant illness or age-related diseases, rather than specific life-limiting diagnoses (10). It could be argued the RAC facilities are one of the main provider of palliative care often without the support of Hospice (3, 10, 11). In order for RAC facilities to deliver high-quality palliative care, facilities require adequate resources, adequately trained staff, and access to specialist palliative care (2). However, RAC in New Zealand is faced with the challenges of organisational conditions characterised by increasing workload, low staffing levels and high staff turnover (12).

In New Zealand, as in other developed countries, the growing patient population means there is an urgent need to invest in the development of “generalist palliative care”(13). As defined by the New Zealand Ministry of Health (13) generalist palliative care is care “provided for those affected by life-limiting illness as an integral part of standard clinical practice by any health care professional who is not part of a specialist palliative care team”. However, health professionals often feel ill-prepared to provide effective palliative care, especially surrounding the discussion of death and dying, and being able to communicate effectively with families during the end of life period (4, 14, 15). Advanced Care Planning (ACP) is one example of these hard to have conversations, which involves shared planning between the RAC resident, their family and the RAC health professionals on the important values and wishes for the end of life, and includes incorporating these into the resident’s care plan (4). Having healthcare professionals unskilled in these areas can compromise the care provided to residents and their families, as well as create added stress during the end of life (14, 15).

Traditional educational interventions (e.g. short training courses, online modules) have had varied success (10, 16, 17). In New Zealand, healthcare professionals within RAC settings work within a context of too few staff and high turnover (17). The burnout that results from these conditions, can negatively impact the uptake of these didactic courses (18). Furthermore, didactic courses have proven to be unsuccessful in producing sustained knowledge transfer (4, 18, 19).

The Supportive Hospice and Aged Residential Exchange (SHARE) intervention sought to fill the gap in palliative care education for residential aged care staff. SHARE included focused palliative care needs assessment, clinical coaching and role modelling by hospice palliative care nurse specialists which sought to support RAC registered nurses (RN’s) and health care assistants (HCA’s) to put new learning into practice (20). SHARE used a reciprocal model enabling the palliative care nurse specialists to also learn from RAC staff about the palliative care needs of older adults with chronic conditions(20) The components of SHARE include: clinical coaching by hospice palliative care nurse specialists, support with

the development of care plans that reflect the palliative care needs of residents with a life-limiting illness, role modelling of conversations with families related to palliative care, and debriefing amongst all RAC staff following a resident's death. The building of relationships between Hospice and facility staff, and consequently facility staff and residents and their families, underpins successful implementation of the intervention(21).

The SHARE intervention was implemented over a year in 20 urban RAC facilities across two district health boards (DHBs) in Auckland. This report forms part of a larger mixed-method evaluation of SHARE which included quantitative assessments of staff palliative care delivery confidence, a records review of residents identified as benefitting from a palliative approach to care, as well as qualitative interviews with staff, general practitioners (GP's), facility managers and bereaved families(21).

Role of Families. Families play a key role in a resident's ongoing care and also act as the closest link to residents' views of care received (22, 23) Previous research has identified shortfalls in the management of the transition to palliative care in RA from the family perspective (24). In particular, research has identified RAC staff members having difficulty communicating information about residents' likely prognosis to family members (25), as well as engaging families in care planning(24). Additionally, families have expressed dissatisfaction due to a general practitioner's' inaccessibility and/or changes in the general practitioner responsible for the care(26). These difficulties create barriers to the formation of a 'partnership' between staff and family which could enhance the quality of care (27), of particular importance at the end of life. It is the experience of palliative care delivery for residents and their family members that the SHARE intervention was designed to improve and therefore is a fundamental aspect of SHARE as a whole. Exploring bereaved family perceptions of palliative care delivery for their relative during SHARE is key to developing improvements in the intervention.

Method

Aim

The aim of the study was to describe bereaved family member's experiences of palliative care for their relative in RAC facilities implementing SHARE. This study makes up a part of a larger mixed-methods evaluation of the SHARE intervention in 20 RAC facilities. The evaluation utilised both quantitative (survey, records review) and qualitative methods (interviews and focus groups) to assess the impact and sustainability of the intervention.

Design

This study views participants as sources "situated knowledges"(28, 29) reflecting patterns of meanings and beliefs not preordained by an existing theory(30). A qualitative descriptive design was adopted to explore the experiences of 16 bereaved family members regarding palliative care delivery for their relative in RAC facilities implementing SHARE. Bereaved family participants provided a situated account of the

facilitators and contextual challenges to palliative care delivery observed during SHARE implementation(30).

Process

Bereaved family members were recruited through the 20 RAC facilities that implemented SHARE across two urban district health boards (DHB's). Out of the 20 facilities contacted, nine facilities responded with contact details for bereaved family members interested in participating. All participants had a family member die in the past year in RAC. Bereaved families were recruited from RAC facilities at two different time points in SHARE implementation: RAC less than one month into the implementation of SHARE (start) and RAC facilities who had implemented SHARE for one year (finish). Drawing on the constant comparative method outlined by Boeije (31) interviews from two different groups were compared with regard to the experience of a specific phenomenon (SHARE). Analyst triangulation(32) of the results was established through discussion with project co-authors who hold a variety of expertise (gerontology, palliative care, social psychology, ethnography).

Participants were interviewed using a semi-structured interview schedule developed during the pilot study (20). The interview schedule explored psychosocial impacts including satisfaction with life, communication skills, grief, loss, and survivor guilt/shame (see Appendix). Interviews of approximately 60 minutes of duration were audio-recorded with participant permission. Interviews were transcribed verbatim by a transcriptionist who had signed a confidentiality agreement. All data collection took place between November 2017 and April 2019. All bereaved family participants were assured of anonymity, confidentiality and their right to withdraw from the study at any time. Ethics approval for the study was obtained from the university ethics committee Ref # 020075.

Analysis

Transcripts were uploaded to the analysis software QSR NVivo 12. SB conducted a reflexive thematic analysis, developing themes and sub-themes related to the characteristics associated with family perceptions of palliative care delivery. (33). First, immersion in the data was achieved by reading transcripts several times and creating memos based on general themes constructed. Then, open coding was utilised and a number of codes were generated across the data set. Codes were labelled using terms used by the participants or relevant to the literature. Codes were then collapsed into broader categories. The list of broader categories was then condensed further into main categories and then candidate themes. Candidate themes were reviewed against the transcripts and refined to reflect patterns of shared meaning represented in the transcripts. The constant comparative method was then used to identify whether SHARE duration shaped the experience of the previously identified themes. In other words, "what did bereaved families at the start of SHARE say about developed themes and what did bereaved families at the finish of SHARE have to say about the same themes?" "through the concrete experiences of the

bereaved families(34). In line with previous research (35) coding of all transcripts was completed to develop themes before comparisons between the two groups of interviews were undertaken.

Results

Participants

All participants were family members of decedent residents identified as possibly benefitting from a palliative approach to care through SHARE. Participants' ages ranged from 40–80 years of age. The majority of interviewees were women, with four out of 16 interviewees being men. The types of relationships to the deceased were either a child (n = 13), spouse (n = 3), or sibling (n = 1). Interviewees represented mostly NZ European ethnicity, with two of 16 participants stating their ethnicity as different to NZ European. This was mirrored also in the home language spoken. To protect the confidentiality of both participants and the residential aged care facilities, quotes from participants were assigned pseudonyms based on a colour (e.g. emerald, garnet etc.) (Table 1).

Table 1
Demographic Overview of Interview Participants

	<i>Start-SHARE</i>		<i>Finish-SHARE</i>	
	<i>(n = 8)</i>		<i>(n = 8)</i>	
	Frequency	%	Frequency	%
Age group				
<i>40–49</i>	<i>1</i>	<i>12.5</i>	<i>0</i>	<i>0.00</i>
<i>50–59</i>	<i>0</i>	<i>0.00</i>	<i>2</i>	<i>25.0</i>
<i>60–69</i>	<i>0</i>	<i>0.00</i>	<i>2</i>	<i>25.0</i>
<i>70–79</i>	<i>7</i>	<i>87.5</i>	<i>4</i>	<i>50.0</i>
Gender				
<i>Female</i>	<i>6</i>	<i>75.0</i>	<i>6</i>	<i>75.0</i>
<i>Male</i>	<i>2</i>	<i>25.0</i>	<i>2</i>	<i>25.0</i>
Ethnicity				
<i>NZ European</i>	<i>7</i>	<i>87.5</i>	<i>7</i>	<i>87.5</i>
<i>Māori</i>	<i>1</i>	<i>12.5</i>	<i>0</i>	<i>0.00</i>
<i>Asian</i>	<i>0</i>	<i>0.00</i>	<i>1</i>	<i>12.5</i>
Language				
<i>English</i>	<i>7</i>	<i>87.5</i>	<i>7</i>	<i>87.5</i>
<i>Te Reo Māori</i>	<i>1</i>	<i>12.5</i>	<i>0</i>	<i>0.00</i>
<i>Chinese (Mandarin or Cantonese)</i>	<i>0</i>	<i>0.00</i>	<i>1</i>	<i>12.5</i>
Religion				
<i>No Religion</i>	<i>2</i>	<i>25.0</i>	<i>3</i>	<i>37.5</i>
<i>Christian</i>	<i>5</i>	<i>62.5</i>	<i>3</i>	<i>37.5</i>
<i>Buddhist</i>	<i>1</i>	<i>12.5</i>	<i>1</i>	<i>12.5</i>
<i>Spiritualist</i>	<i>0</i>	<i>0.00</i>	<i>1</i>	<i>12.5</i>
Relative Dementia diagnosis	<i>3</i>	<i>37.5</i>	<i>3</i>	<i>37.5</i>

Themes

Four themes outlined key components of palliative care that were important to relatives' experience: communication with staff, relationship with GP's, systems of care, and hospice involvement. Comparisons in the above themes between the experiences of bereaved families at the start of SHARE and at the finish are represented as subthemes. A fifth theme, entitled 'challenges' outlined challenges in the "time available to care". These challenges (staff shortages and turnover) were perceived by families as continuing barriers to achieving better palliative care for their relatives. (Fig. 1)

Communication of resident condition:

Start-SHARE

Lack of awareness. A key part of the SHARE intervention was teaching nurses how to effectively communicate with families about the transition to a palliative care approach and what to expect. Some family members described not finding out their family member was approaching the end of life until days before their relative's passing.

Right, did the staff explain to you what might happen, the process of his dying? Did they talk to you about that, you might expect this or he might do this?

No, nothing like that.

Interviewer: So you had no idea what was going to happen, or how?

No, none at all, none at all. (Emerald)

Finish-SHARE

Greater Awareness. At the end of SHARE, however, while most of the relatives had no knowledge of any pathways (e.g. Liverpool Care Pathway) that their relative might be on, they did know when they were dying. Many family members recalled making advanced care plans, alongside an RN and their relative. Many also recall being told their relative was heading towards the end of life. For many families, this allowed them to organise family before their relative died, and created an environment that was less distressing before death. The following quote outlines the planning and communication between RAC staff and the family member that allowed for a better-perceived death.

But you know, they took me aside and made sure that I understood what the, what the process was and how it would work. And to make sure that I actually understood - I guess that's prior to them starting the morphine, it was pretty obvious by then... And they got her stable and I wasn't going to go home, but they got her stable and she was quite good. And I went home, I'm one of five so I contacted all my siblings and said, look Mum's not in a good space but she's stable, but I just think you need to know this. You know, if you're available to come in tomorrow that would probably be a good idea to see her. (Alba)

Relationship with GP

Start-SHARE

Concerns. Overall the relationship with the GP was a concern. One participant was so angry with the GP's attitude towards her and her father that she made an official complaint. This seemed to be the result of the doctor and nursing staff not communicating well and this resulted in the GP writing an apology to the daughter. Another felt that the GP just went through the motions and did not show any concern for her mother's welfare:

Interviewer: On a scale of 1–5?

She would be on the lower [end], she might have been an efficient person, but mum couldn't stand her. She was absolutely useless in end of life care; she didn't care less about mum.

Oh we complained, my daughter complained badly about the doctor's attitude, etc, etc, so we've got a big, long letter of apology from her, and why she did what she did. (Indigo)

The above respondent talked about the lack of communication between the staff and the GP. There appeared to be no syringe driver on site and there were difficulties getting one as well as the medication to put in it; finally this was completed through advice from the hospice GP and the facility.

Finish-SHARE

Continued concerns. Overall there was still a varied response to the communication with GP's. One participant had moved her mother from one facility (A) to another facility (B) and GP was vigilant in finding out why her blood test results were not right, whereas in facility (A) she had been on iron tablets for a long time. Her daughter was pleased that the GP was concerned enough to follow this through:

As soon as she got into facility (B) the Doctor there said her bloods aren't right, which I'd known from the one up in facility A, but they just kept giving her iron tablets. And she and the Doctor at facility (B) said, no, we need to find out why her bloods aren't right. So they sent her to Hospital, so within a week of her coming down here she was sent to the Hospital. (Garnet)

Many did not see the GP at all and relied on communication and information through the nurse manager. Not seeing the GP did not concern them as they were aware the GP rounds were at times that the relatives were not able to be available:

I never saw a Doctor. I never saw the Doctor, this was all with the Head Nurse. Never saw the Doctor. Mum liked the Doctors. Yeah, she [said] to me the young guy was very handsome and she said, you should meet him. I said, oh really? Really? But no, I never met them, but I got full feedback, so I was quite happy and, and whatever they said was gonna happen happened. I'd go down there and they'd say, no we've spoken to the Doctor, we've got an increase for her pain allowance stuff. (Crimson)

However, some participants found their lack of interaction with the GP worrying and disturbing:

Interviewer: Did you see the Doctor at all?

Nope. Had no faith in him.

Interviewer: Did you not?

Yeah. There were, there were many times I asked, when does he visit this place? Can I make an appointment please to see him? I'd like to sit with him and my sister. The only, the only medical professions I had, had face to face consultation with was the hospital. [Family member] and I said, yay, we'd like to speak to her Doctor. Nothing. (Cyan)

Systems of Care

Start-SHARE

Systems failures. All the families spoke highly of the care. Only one expressed that there was the “odd carer [healthcare assistant] who didn't have quite the empathy I would expect” but generally they spoke highly of the healthcare assistants and how they went to extra lengths to do things that made the resident happy and comfortable.

They took a mental note and they would, you know they would act on it or, you know they'd poke their head in and say something appropriate. They also took care to put the right amount of sugar into his tea. It was just a genuine, it was just a genuine care, I couldn't say love, but it felt like that (laughter), but it felt like a genuine care for him, and me, and our needs, and our privacy. (Blue)

Systems of care sometimes let families down, especially when it came to caring for people with dementia:

He had a fall in the bedroom, that's right, he fell and hit his mouth on the dressing table. And of course, there was blood and everything, so I took him down to [urgent care], that was it, and they said they couldn't do the plastic surgery. So we went out to [hospital], I took him out to [hospital], so they examined him out there. They said they couldn't do anything that night because he was on Warfarin, so we were sent home from [hospital] and then told to come back the next morning at seven. Am I allowed to say haha? (Emerald)

Finish-SHARE

Level of Care. Some families had previous experience with families in Hospice and compared the care capacity in Hospice to the care provided to their relatives in RAC.

That was, I'd say the Hospice was just, just another level, another level, yeah, another level – Of skill... another level of skill, you felt completely like, wow, wow. Whereas at the Rest Home they were good but you're sort of like watching and just not the same skill level. No, that's exactly what it was. Yep. (Crimson)

Despite this perceived difference between Hospice and RAC facilities, many families felt like their relative was well cared for at the end of SHARE, and talked of the nurses' ability to provide care that was more than adequate for someone who was bed-bound at the end of their life. For many families, this created ease of mind knowing that their family member was being well looked after.

The Nursing staff were meticulous and caring, in fact, she had had a, a bed ulcer from, she'd, her MS [Multiple Sclerosis] was at the stage where she would have to lie still all night. So that's kind of ten to

twelve hours every night. Yep. Without turning. And she'd developed a couple of ulcers managed to get rid of those. Which is quite something aged 92. (Teal)

Hospice Involvement

Start-SHARE

Lack of input. Another key aspect of SHARE was a collaboration between Hospice Palliative Care Nurse Specialists and RAC staff, particularly RNs and formal caregivers. At the start of SHARE, family members did not report Hospice having any input in their relative's care, or that this was even an option for them.

Interviewer: And hospice wasn't involved with your Dad?

No.

Interviewer: No, no, okay.

No, we didn't have any hospice people at all.

Interviewer: And you weren't asked about it?

No, no we weren't. I don't know, is that an option, can you get that? I wouldn't have a clue. No, we were never, that was never offered or asked. (Grey)

Finish-SHARE

Input. Having the SHARE intervention integrated into palliative care provision within RAC facilities meant there was a collaboration between Hospice Palliative Care Nurse Specialists and RAC staff. As a result, some families were aware of Hospice involvement in their care, although this was still primarily for residents with cancer diagnoses. More generally, however, the presence of the Palliative Care Nurse Specialists seemed to aid families in feeling more aware of the process of dying and offered them extra support for what would happen after death. In this way, families felt looked after and involved in their relative's passing.

According to Mrs. H, she remember [Nurse X] and some other Nurses, they are coming from Hospice, have talked to her about [resident] is dying, what she need to do. They have people talk to her about making an arrangement for the funeral. She even remember they have explained to her a few days before [resident] died they are going to give him a small dose of... to five milligrams of morphine, how they going to care for him. So those part she was very much involved and have conversation. (Navy)

Continuing Challenges to the Culture of Care

Start-SHARE

Time to care. Family members had highlighted the extra attention to details that helped both residents and family members feel more comfortable. For example, prior to SHARE many family members related that their relatives were always nicely dressed and that the carers had made a special effort with shoes and also jewelry.

She was always dressed beautifully – they would put a necklace on her, and especially the Filipino nurses/carers [healthcare assistants], they were lovely. (Emerald)

Finish-SHARE

Fewer Staff. A private funding model for the facilities in this study created increasing challenges for the implementation of SHARE. Three of the participants talked about staffing levels, and two had relatives at the same facility where there was an obvious shift in the numbers of staff and also the culture of care. Both interviewees noted that staff suddenly had less time for their relatives, and while they did their job

satisfactorily, it was completed quickly with less time allocated and less conversation. One relative specifically went in to feed his father because he knew that the staff did not have time:

Even his, like at the end he needed to be fed. So I'd go and make, I always went over and well I left here about 10:30, 11 so I was there for lunch, give the staff some time. And they, they appreciated it. You know.

Interviewer: Did you notice that? That they were pressed for time.

Oh yeah, well I know that, so that's why I did it. I know that they have, well I know, 60 was it, 65 there and there's three girls at lunch trying to get them all fed. So they haven't got time to feed each and everyone that required it. (Azure)

Definitely. Definitely fewer staff. And that was a large part of it too. They always, you know, would be like, oh we're so understaffed and, I didn't often have a need to ring the bell but on a couple of times that I did, you know, it might be a toileting issue that I, I needed help with... And in situations like that, you would wait you know, to the point where like just sit there Mum and don't move. And I'd go off looking for somebody. They hadn't come to answer the bell. (Alba)

Turnover. Some commented that the staff would change continually, especially for those residents who had been at the facility over a number of years. This became confusing for next of kin, who dealt with it by by-passing the health care assistants and going to the nurse manager for any information:

Because they were so different, different people there all the time and I'd ask where's such and such? Where's so and so? And, and John would be doing the same, and it got to the stage where we didn't want to ask, you know. So if we had a problem we'd go and see the manager. (Cyan)

Discussion

Findings indicated that good communication can play an integral role in the family experience of palliative care for their relative (36). Poor communication has been linked to detrimental outcomes for families including increased difficulty in decision-making and a lack of preparedness for a relative's death, impacting on bereavement (37, 38). At the start of SHARE and consistent with previous research (39), bereaved family members of RAC residents, felt uninformed about the residents' health and felt that they were not given information on what to expect at the end of life. In line with previous research(24, 40), bereaved family perceptions of quality of care appeared improved at the finish of SHARE by earlier communication among residents, family members, and health professionals about prognosis, options for care, and assessment of support and coping resources.

Interviews after a year of SHARE indicated that more communication and collaboration between Hospice and RAC facilities led to positive responses by families regarding the quality of care for their relatives (4, 8). Reflecting previous research (8) a poor relationship between hospice and RAC facilities was a source of family concern prior to SHARE. After a year of SHARE, the collaboration between hospice and RAC promoted bereaved family member confidence in the care of their relatives. Family members of residents with a cancer diagnosis were more likely to be aware of the presence of hospice. However, the presence of hospice was felt more indirectly in the improved communication concerning their relatives' changes in condition.

Communication with GPs, while perceived by bereaved family as improved somewhat at the end of SHARE, continued to be an area of difficulty. A recent study looking at the experiences of family members as their relatives transitioned to palliative care supports these results (24), that better communication at the end of life, especially with GPs, would have improved their relative's experience at the end of life. There are many potential reasons for bereaved families' expressed dissatisfaction in communication with GPs. First is the obvious time restraints that all medical professionals face. For GPs, this often means spending only a few hours a week doing rounds in a RAC facility and making decisions for residents within this time (41). As a result, the time available for communicating at length with residents and their families is not available (42). However, many of the cases of poor communication and care from GPs from families in this study focused on the way in which communication was handled, and the extent to which GPs showed respect for residents and families. Literature suggests the lack of palliative care training available for GPs, compounded with time pressures, leads to a lack of effective communication skills at the end of life, and can negatively impact the level of care felt by residents and their families (43). It should be noted however, that SHARE was an intervention directed at improving the palliative care knowledge and skills of the RAC nursing and health care assistant staff and not GP's. Future implementations should incorporate greater involvement of GP's from the start of SHARE.

The quality of care throughout SHARE was perceived by bereaved families to be good. All participants expressed the sentiment that their relative was treated with dignity and respect. Indeed, bereaved families found relationships to be a fundamental aspect of good palliative care. It is well known now that forming a rapport/relationship within a professional-patient context allows for better care to be provided, and for better uptake of care, especially when care is critical (44–46). Many bereaved families spoke of the role health care assistants specifically played in making their relative comfortable and happy at the end of life. While care quality continued to be seen to be good, bereaved family continued to express concerns about low staffing levels and staffing changes after a year of SHARE. Poor staffing levels, high turnover, and associated time pressures can threaten the continuity of care within RAC (47). Since relationships between residents, families, and staff are at the heart of good palliative care, time pressures and increasing staff turnover created barriers to the formation of enduring relationships between families, residents, and staff. Continuing family concerns over the stability of the workforce may impact upon both confidence in RAC staff and the sustainability of the intervention.

Strengths and limitations

Only the views and experiences of bereaved family members are included in these findings. The views of RNs, GPs, HCA's, and PCNSs have been presented elsewhere (4, 42, 48). Nevertheless, the experiences of these bereaved family members provide both a unique insight into the benefits and challenges to the implementation of SHARE(49). Interviews were carried out within 12 months of a relative's passing to both lessen the burden on the interview participant, and to ensure they could recall details from their relative's passing (50). A further limitation was the absence of Māori and Pacific Island representation. It is well established that Māori and Pacific peoples suffer historic and institutional health disparities (51).

In a New Zealand context, Māori and Pacific Island perspectives and experiences are imperative to ensuring the SHARE project has equitable outcomes.

Conclusion

Good palliative care delivery requires both resident and family-centred care(8). Findings from the study support the view that bereaved families perceived both improved communication and increased support through the end of life journey of their relatives at the conclusion of SHARE. Issues in communication with GP's and bereaved family perceptions of the negative impacts of staffing shortages on relative's care continue to present challenges to SHARE implementation. Both are complex issues that must be addressed to improve palliative care for RAC residents and families alike.

Declarations

Ethical Approval

Ethics approval for the study was obtained from the University of Auckland Human Participants Ethics committee Ref # 020075.

Consent

All participants signed consent forms to participate and agreed to the de-identified publication of their responses as a part of that consent.

Availability of data and materials

De-identified data is available upon request.

Competing Interests

None declared.

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Authors Contributions

All authors were involved in the conception, design, and implementation of the research. SB, RF, DB, JR MG, and MB were involved in the data analysis and interpretation and drafting of the paper. All authors were involved in the review and approval of the final article for publication.

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Figures

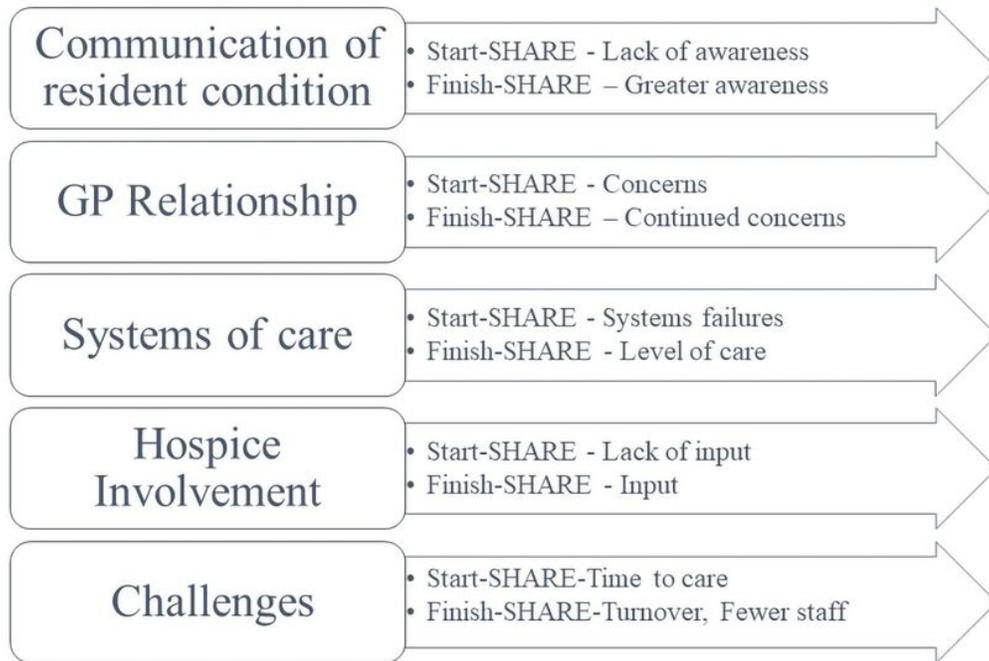


Figure 1

Bereaved Families Experiences of Palliative Care Delivery in SHARE RAC Facilities: Themes and Sub-themes

Supplementary Files

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