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Experiences of Bereaved Families Following the SHARE Model of Palliative Care in Aged Residential Facilities

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Abstract

The Supportive Hospice Aged Residential Exchange (SHARE) represents an innovative model of palliative care education tailored for residential aged care settings. Its purpose is to enhance clinical staff capability in providing high-quality palliative care within aged care facilities while strengthening specialist palliative care nurses' competencies in supporting frail older adults. This study explored the perspectives of 18 bereaved family members regarding their relatives' palliative care experiences at two time points—before and after a one-year SHARE implementation—using semi-structured interviews. Bereaved families emphasized three key aspects shaping their experiences: communication with staff, care systems, and the role of hospice involvement. Subthemes revealed notable improvements in these domains over the implementation period. However, persistent challenges—such as difficulties in GP relationships, staff shortages, and workforce turnover—were also identified. The findings suggest that SHARE positively influenced families' end-of-life experiences, primarily by fostering better communication and support. Nevertheless, ongoing workforce and systemic issues continue to pose barriers to optimal care.

Keywords: Palliative care, Bereavement, Residential aged care, Older adults, Hospice education

Introduction

New Zealand, similar to other high-income nations, is facing a significant demographic shift towards an older population. By 2035, nearly a quarter of the population is projected to be aged 65 or older [1]. Older age is frequently associated with frailty, multiple chronic conditions, and an increased demand for complex healthcare, particularly near the end of life [2]. Between 2003 and 2007, 38% of deaths among New Zealanders over 65 occurred in residential aged care (RAC) facilities [3]. In the New Zealand context, RAC encompasses a spectrum of long-term care services—including hospital-level care, rest homes, and dementia-specific care—designed to meet varying levels of resident need [4]. The sector is predominantly privately owned, with large facilities comprising the majority of providers [3]. By the end of 2019, there were approximately 39,000 RAC beds nationwide, with projections indicating a requirement of around 52,000 beds by the decade's end [1]. If current patterns persist, most individuals aged over 85 are likely to die within RAC, highlighting the growing demand for advanced geriatric and multi-morbidity care in these settings [5, 6]. Consequently, RAC facilities are under increasing pressure to provide high-quality palliative and end-of-life care [7].

Palliative care aims to optimize the quality of life for individuals with life-limiting conditions while supporting their families during illness and after death [2]. It forms an essential part of overall healthcare planning, often complementing or replacing purely treatment-focused approaches for those at the end of life [8]. Palliative care

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can be delivered by generalist healthcare providers as part of routine clinical practice or by specialist practitioners who have received dedicated training [2]. Hospices in New Zealand provide both inpatient and outpatient services for patients with terminal or life-limiting illnesses [9]. For many older adults in RAC, palliative care is required in the context of complex chronic conditions rather than only cancer [10], and RAC facilities often deliver this care independently, sometimes with minimal hospice support [3, 10, 11]. Delivering high-quality palliative care in these settings requires sufficient resources, trained personnel, and access to specialist support [2]. However, RAC facilities frequently contend with staffing shortages, high workloads, and significant turnover, which can compromise care quality [12].

As in other countries with ageing populations, New Zealand faces an urgent need to strengthen generalist palliative care provision [13]. The Ministry of Health defines generalist palliative care as care for those with life-limiting conditions provided as part of routine practice by healthcare professionals outside specialist teams [13]. Despite this, many healthcare workers report feeling unprepared to address end-of-life needs effectively, particularly in initiating conversations about death and dying or communicating with families [4, 14, 15]. Advance Care Planning (ACP) exemplifies these complex discussions, requiring collaboration between residents, their families, and RAC staff to document individual preferences for care at the end of life [4]. Lack of proficiency in these areas can negatively impact resident care, increase family stress, and exacerbate workforce strain [14, 15].

Traditional educational approaches—such as brief workshops or online modules—have demonstrated inconsistent effectiveness [10, 16, 17]. Staff in RAC frequently operate under conditions of low staffing and high turnover, contributing to burnout and limiting engagement with didactic training programs [17, 18]. Furthermore, conventional courses often fail to achieve lasting improvements in knowledge or practice [4, 18, 19]. To address these gaps, the Supportive Hospice Aged Residential Exchange (SHARE) program was developed.

SHARE involves a structured series of activities led by a hospice nurse specialist, including weekly visits over one year to each RAC facility. Initial visits focus on reviewing residents to identify palliative care needs using the Clinical Frailty Scale [20] and the Supportive and Palliative Care Indicators Tool (SPICT) [21], in collaboration with RAC nurses. Identified residents become the focus of ongoing discussions. SHARE also incorporates clinical coaching, role modelling, tailored teaching sessions, guidance on ACP conversations, and staff debriefing after resident deaths [22].

By combining new learning with existing skills, SHARE aims to enhance both RAC staff competence and specialist nurses' expertise in gerontology. Qualitative analysis of nurse reflections highlights that sustained relationships with RAC staff are central to successful implementation [4]. Overall, SHARE serves as a mechanism for knowledge exchange between hospice and RAC teams, supporting improved palliative care delivery.

Implemented over one year in 20 urban RAC facilities across two district health boards, SHARE was evaluated through a mixed-methods approach, including quantitative assessments of staff confidence, review of residents receiving palliative care, and qualitative interviews with staff, general practitioners, facility managers, and bereaved families [23].

Role of families

Families are integral to the ongoing care of residents in RAC facilities and serve as critical informants regarding how residents perceive the care they receive [24, 25]. Prior studies have highlighted gaps in how transitions to palliative care are managed from the perspective of families [26]. Specifically, RAC staff often encounter challenges in effectively communicating prognosis and anticipated care needs to family members [27] and involving them in care planning processes [26]. Additional issues arise from the unavailability or frequent turnover of general practitioners responsible for residents' care, which has been reported as a source of dissatisfaction for families [28]. These challenges can hinder the development of collaborative relationships between staff and families, which are essential for enhancing care quality, particularly at the end of life [29]. The SHARE intervention was designed to address these gaps by improving palliative care delivery for residents and their families. Recognizing the pivotal role of families in care provision, this study explored how bereaved family members' perceptions of palliative care evolved during SHARE implementation, with the aim of identifying areas for improvement in future iterations of the program.

Materials and Methods

Aim

The objective of this study was to examine bereaved family members' experiences of palliative care for their relatives within RAC facilities implementing the SHARE program. This study forms part of a broader mixed-methods quasi-experimental evaluation of SHARE across 20 RAC facilities. The larger evaluation incorporated both quantitative approaches (surveys and records reviews) and qualitative methods (interviews and focus groups) to assess the intervention's impact and sustainability.

Design

This study adopts the perspective that participants provide "situated knowledge" [30, 31], offering insights shaped by their own experiences and context rather than by pre-existing theoretical frameworks [32]. A qualitative descriptive approach was employed to explore the experiences of 18 bereaved family members regarding palliative care delivery within SHARE-implementing RAC facilities. Participants offered detailed accounts of the facilitators and barriers encountered during SHARE implementation [32]. Comparison is central to qualitative inquiry [33]; following Boeije's constant comparative method [34], interviews from families at different stages of SHARE implementation were analyzed comparatively. The study focused on understanding how themes raised by families prior to SHARE differed from those observed after one year of SHARE implementation.

Process

Bereaved family members were recruited through the 20 RAC facilities participating in SHARE across two urban district health boards. Of these, nine facilities provided contact information for families willing to participate. Eligible participants were family members of residents who had passed away within the preceding year. Recruitment occurred at two time points: at the start of SHARE implementation (less than one month) and at the end of a one-year implementation period. The final number of interviews was determined based on achieving conceptual saturation—collecting sufficient evidence to thoroughly explain identified themes [35].

Semi-structured interviews, lasting approximately 60 minutes, were conducted using an interview schedule developed during a pilot phase [22]. Topics explored included psychosocial impacts, communication experiences, grief, loss, survivor guilt, and overall satisfaction with care. With participants' consent, interviews were audio-recorded and transcribed verbatim by a confidentiality-bound transcriptionist. Data collection took place between November 2017 and April 2019. All participants were assured of confidentiality, anonymity, and the right to withdraw at any stage. Ethical approval was obtained from the university ethics committee (Ref #020075).

Analysis

Transcribed interviews were imported into QSR NVivo 12 for organization and coding. SB carried out a reflexive thematic analysis to identify themes and sub-themes relating to bereaved families' perceptions of palliative care delivery [36]. The process began with repeated readings of the transcripts to gain deep familiarity with the data, accompanied by memo writing to note emerging patterns and general impressions. Initial open coding was then performed, generating multiple codes drawn directly from participant language or informed by the literature. These codes were subsequently grouped into broader categories, which were further refined into main categories and potential themes.

Candidate themes were reviewed against the raw transcripts to ensure they accurately reflected shared meanings across participants. A constant comparative approach was applied to examine how experiences differed according to the stage of SHARE implementation, addressing the question: "How do families at the start of SHARE perceive these themes compared with families at the conclusion of SHARE?" [37]. In line with established qualitative methods [38], all transcripts were fully coded before comparisons between the pre- and post-intervention groups were undertaken. Analyst triangulation was employed by discussing emerging themes with co-authors from diverse fields, including gerontology, palliative care, social psychology, and ethnography, to enhance the credibility and trustworthiness of the findings [39].

Results and Discussion

Participants

The qualitative approach aimed to gain rich insight into bereaved family members' experiences of palliative care for relatives in RAC facilities. Demographic information was collected in conjunction with the interviews to provide context.

Eight interviews were conducted with bereaved family members prior to SHARE implementation, comprising seven women and one man. Most participants were aged 70–79, identified as New Zealand European, and reported Christianity as their religion. Among the deceased relatives represented in this group, five had a diagnosis of dementia **(Table 1)**.

Following one year of SHARE, ten interviews were completed with bereaved family members. The majority were female (n = 7) and of European ethnicity (n = 8), with half aged 70–79 years. Among the deceased relatives post-intervention, half had a diagnosis of dementia. For both pre- and post-SHARE groups, most deceased residents had been unwell for less than one year at the time of death **(Table 1)**.

To maintain confidentiality of participants and facilities, pseudonyms derived from colors (e.g., Emerald, Garnet) were assigned to all interview quotes.

Here is the paraphrased table with the same structure and information:

Table 1. Demographic Overview of Interview Participants.

Category	**Start-SHARE (n=8)**		**Finish-SHARE (n=10)**	
	Frequency	%	Frequency	%
Age group				
40–49 years	1	12.5	1	10.0
50–59 years	2	25.0	2	20.0
60–69 years	1	12.5	2	20.0
70–79 years	3	37.5	5	50.0
80+ years	1	12.5	0	0
Gender				
Female	7	87.5	7	70.0
Male	1	12.5	3	30.0
Ethnicity				
NZ European	8	100	8	80.0
Māori	0	0	1	10.0
Asian	0	0	1	10.0
Language				
English	8	100	8	80.0
Te Reo Māori	0	0	1	10.0
Chinese (Mandarin or Cantonese)	0	0	1	10.0
Religion				
No Religion	3	37.5	4	40.0
Christian	4	50.0	4	40.0
Buddhist	0	0	1	10.0
Judaism	1	12.5	0	0
Spiritualist	0	0	1	10.0
Dementia Diagnosis				
Yes	5	62.5	5	50.0
No	3	37.5	5	50.0
Length of Illness				
Less than 7 days	1	12.5	3	30.0
1–4 weeks	5	62.5	2	20.0
Over 1 month, under 1 year	2	25.0	4	40.0
1 year or more	0	0	1	10.0

The table maintains all original data, with rephrased headers and labels for clarity while preserving the structure.

Themes

Analysis identified three primary themes reflecting aspects of palliative care that were particularly meaningful to bereaved family members: communication with staff, the organization of care systems, and the involvement of hospice services. Differences in these themes between families interviewed at the start of SHARE and those at the conclusion were captured as subthemes **(Figure 1)**. A fourth theme, labeled **"challenges,"** highlighted ongoing issues that persisted throughout the SHARE intervention. Subthemes within this category included relationships with general practitioners, staffing shortages, and staff turnover. Families reported that these challenges continued to impede the delivery of optimal palliative care for their relatives.

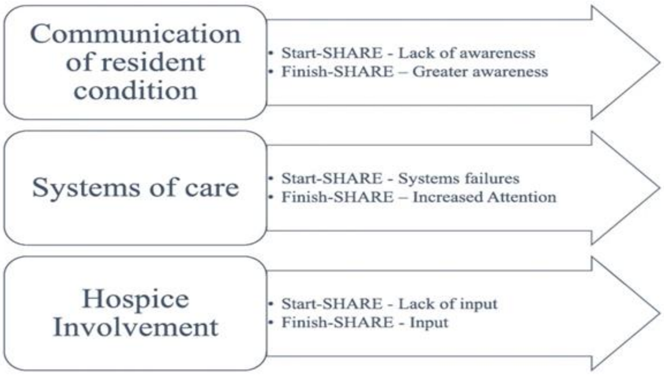

Figure 1. Bereaved Families Experiences of Palliative Care Delivery in SHARE Residential Aged Care Facilities: Themes and Sub-themes

Communication of resident condition
Start of SHARE – limited awareness
At the outset of SHARE, many family members reported that they were not informed about the progression of their relative's illness or the transition to end-of-life care until very close to the time of death. The SHARE intervention aimed to educate nurses on how to communicate effectively with families about the palliative process and what to expect. However, some families described a complete lack of guidance regarding what would happen as their relative approached death.
"Did the staff explain what might happen, or how he might die?"
"No, nothing like that… no idea at all." (Emerald)

End of SHARE – improved awareness
By the conclusion of SHARE, families generally had a better understanding of their relative's condition, even if they were unfamiliar with specific care pathways such as the Liverpool Care Pathway. Many recalled engaging in advance care planning with registered nurses and being informed when their relative was nearing the end of life. This allowed families to coordinate visits and prepare for the final stages, reducing distress and creating a calmer environment.
"They took me aside to explain the process and made sure I understood before starting morphine. I was able to contact my siblings and plan visits, which helped us all feel more prepared." (Alba)

Systems of care
Start of SHARE – system gaps
Initially, families reported that organizational systems sometimes failed to meet the needs of residents, particularly those with dementia. Delays and unclear processes when accessing care were common sources of stress and frustration.
"He had a fall and hit his mouth. We were sent between urgent care and hospital, told to return the next morning… it was confusing and stressful." (Emerald)

End of SHARE – enhanced attention
After SHARE was implemented, families observed improvements in the organization of care. End-of-life moments were reported as more peaceful, and staff were attentive and communicative about medication changes and medical consultations. Families expressed confidence that their relative received high-quality care and felt reassured by the consistent updates.
"They kept me informed about every change in medication or doctor visits… it really helped me feel included and at ease." (Azure)
"She had the best care and a peaceful dying experience, which gives me great comfort." (Violet)

Hospice involvement
Start of SHARE – limited hospice engagement
At the beginning of SHARE, family members reported minimal or no involvement from Hospice Nurse Specialists in the care of their relatives. Hospice support was neither offered nor discussed, and families were largely unaware that such services could be available.
"No, we didn't have any hospice people at all… we were never asked if that was an option." (Grey)

End of SHARE – active hospice support

Following SHARE implementation, hospice involvement became more integrated within RAC facilities. Families, particularly those of residents with cancer diagnoses, were more aware of hospice contributions. Hospice Nurse Specialists provided guidance on end-of-life processes, including discussions about dying and practical arrangements after death. This engagement helped families feel supported, informed, and included in care decisions, contributing to a greater sense of reassurance and preparedness.

"Nurses from Hospice talked to me about [resident] dying, and what I needed to do. They helped with funeral arrangements and explained medication plans, like giving a small dose of morphine. I felt very involved." (Navy)

Continuing challenges to the culture of care

Relationship with GPs

Interactions with general practitioners remained a persistent concern for families. Some reported experiences of poor communication between GPs and RAC staff, resulting in suboptimal care. One participant described dissatisfaction so severe that it led to a formal complaint and subsequent apology from the GP. Others perceived the GP as indifferent to their relative's welfare, particularly during end-of-life care. Challenges such as limited access to necessary equipment (e.g., syringe drivers) and medications further highlighted systemic gaps, often requiring hospice support to resolve.

"She [GP] was completely useless in end-of-life care; she didn't care about my mum. We had to complain, and only after that did we receive a letter of apology." (Indigo)

GP communication

From the families' perspective, the quality of communication from GPs remained inconsistent. One participant described moving her mother from Facility A to Facility B. In Facility A, her mother had been on long-term iron therapy, but the GP had not clearly explained the rationale or discussed treatment options, leaving the family anxious. In Facility B, the GP recommended further investigations, highlighting the negative impact of poor communication in Facility A:

"As soon as she arrived at Facility B, the doctor said her blood results weren't right. Facility A had just kept giving her iron tablets. The new GP acted quickly and sent her to the hospital within a week." (Garnet)

Several families had minimal contact with GPs and relied primarily on nurse managers for updates. Some expressed frustration and distress over the lack of direct GP interaction:

"Nope. I had no faith in him. I asked many times when he visits, requesting an appointment with my sister, but nothing. The only face-to-face medical contact we had was at the hospital." (Cyan)

Staffing levels

The privately funded model of the RAC facilities created challenges for implementing SHARE. Families noted that staffing levels had decreased in some facilities, resulting in less time for individual residents. While staff performed their duties, care was often rushed, leaving little room for conversation or personalized attention. One relative described personally assisting with feeding due to limited staff availability:

"At the end, he needed help with lunch, so I went over to feed him. Staff were so busy, trying to feed 60–65 residents with just three carers—they appreciated my help." (Azure)

Another participant highlighted delays in responding to calls for assistance, showing how understaffing affected residents' care:

"There were fewer staff. On a few occasions, I had to search for someone to help my mum with toileting because the bell wasn't answered." (Alba)

Staff turnover

High turnover was another ongoing challenge, especially for long-term residents. Frequent changes in personnel created confusion for family members, who often bypassed healthcare assistants to communicate directly with the nurse manager:

"Different staff were coming and going all the time. We didn't know who was who, so if there was a problem, we'd go straight to the manager." (Cyan)

The findings highlight that effective communication is central to the family experience of palliative care in RAC settings [40]. Poor communication has been associated with negative outcomes for families, including increased difficulty in decision-making and reduced preparedness for a relative's death, which can complicate bereavement [41, 42]. At the outset of SHARE, consistent with earlier studies [43], bereaved family members reported feeling uninformed about their relatives' health status and lacked guidance on what to expect during the end-of-life phase [26, 44]. Following one year of SHARE implementation, families perceived improvements in care quality, attributed to earlier and more open discussions with health professionals regarding prognosis, care options, and support needs.

Interviews post-SHARE indicated that increased collaboration between Hospice Nurse Specialists and RAC staff fostered more positive family perceptions regarding the care of residents [4, 8]. Before SHARE, families expressed concerns about the lack of effective engagement between hospice and RAC facilities. After the intervention, families reported enhanced confidence in care, with end-of-life experiences described as calm and dignified. This improvement may be linked to better communication, documentation practices, and modeling of advance care planning discussions by hospice staff [45]. Many families recalled participating in advance care planning alongside registered nurses, which facilitated preparedness and understanding. Future iterations of SHARE could benefit from expanding post-bereavement support for families and incorporating RAC-wide post-death rituals and practices [45].

Despite improvements in communication within RAC facilities, families continued to report challenges in interactions with GPs [24]. Limited contact with GPs was common, and when communication occurred, families often perceived it as insufficient or dismissive [10]. Time constraints, workload pressures, and a lack of formal palliative care training for GPs likely contributed to these ongoing difficulties [46-48]. While SHARE focused on enhancing the skills and knowledge of RAC nurses and healthcare assistants, future implementations might benefit from actively involving GPs from the start to improve family engagement and overall care coordination.

Staffing concerns remained prominent, with families reporting issues related to low staff-to-resident ratios and frequent turnover [49]. These challenges impact the continuity of care and can hinder the development of sustained relationships between staff, residents, and families—an essential component of high-quality palliative care. The ongoing presence of hospice nurse mentors was seen as critical in maintaining care quality amid staffing pressures and turnover, supporting both staff and families through the palliative care process.

Strengths and limitations

This study focused exclusively on the perspectives of bereaved family members, providing unique insight into the perceived benefits and challenges of SHARE [50]. The views of nurses, GPs, healthcare assistants, and hospice staff have been reported separately [4, 47, 51]. Interviews were conducted within 12 months of the resident's death to reduce recall bias while ensuring sufficient detail could be captured [52]. A limitation of the study was the lack of Māori and Pacific Island representation [53], which restricts the generalizability of findings. Given historic and ongoing health inequities in New Zealand, including these perspectives is essential for ensuring SHARE achieves equitable outcomes.

Conclusion

Effective palliative care requires both resident- and family-centered approaches [8]. Families reported that SHARE improved communication and support during the end-of-life journey of their relatives. However, persistent challenges related to GP communication and the impact of staffing shortages continue to affect perceptions of care quality [24, 49]. Addressing these systemic issues is necessary to optimize palliative care delivery for residents and families in RAC settings and to ensure the sustainability and success of interventions like SHARE.

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