End of life in residential aged care -
Bereaved family and manager experiences of a palliative care educational intervention

Rosemary Frey, University of Auckland, Auckland NZ, Sophia Barham, University of Otago, Dunedin, NZ, Deborah Balmer, University of Auckland, Auckland, NZ, Michal Boyd, University of Auckland, Auckland, NZ, Jackie Robinson, University of Auckland, Auckland, NZ, Merryn Gott, University of Auckland, Auckland, NZ

THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND HEALTH SCIENCES
School of Nursing

Background

Previous research has identified shortfalls in the management of the transition to palliative care in residential aged care (RAC)(1). The perspectives of RAC managers and bereaved family carers of former residents are essential in evaluating initiatives to improve palliative care delivery in this setting.

Supportive **H**ospice **A**ged **R**esidential **E**xchange (SHARE) – A Palliative Care Educational Intervention (3)

REVIEW AND ASSESSMENT OF GOALS OF CARE

- Weekly visits to intervention facilities
- All existing residents, SPICT and Clinical Frailty Scale.
- The register of residents identified as having palliative care needs (and likely to be in their last year of life) became the basis for discussion at subsequent meetings.

RECIPROCAL CLINICAL COACHING AND ROLE MODELLING

- Clinical coaching and role modelling of palliative care skills and knowledge is a key component of SHARE. This is a reciprocal process of shared learning between palliative care and aged care.

EDUCATION PLANNING

- Palliative Care Nurse Specialist (PCNS) worked in partnership with staff to facilitate a discussion on the specific learning needs of each facility identifying the priorities for staff in terms of palliative care knowledge and skills.

ROLE MODELLING OF ADVANCE CARE PLANNING CONVERSATIONS

- The PCNS provided guidance and role modelling for the RNs in relation to advance care planning conversations including documentation, discussions with the GP and with the family. The developing relationship between the PCNS and facility staff provided opportunities for effective care coordination.

DEBRIEFING AND REFLECTION

- Debriefing was offered for each death that occurs within the facility, facilitated by the PCNS in partnership with a senior nurse from within the facility.

Implemented in 20 RAC facilities over 12 months in one urban centre in New Zealand.

Aim

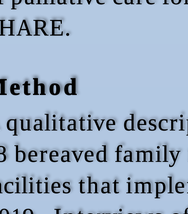
The aim of the study was to describe bereaved family member's experiences of palliative care for their relative in the 20 RAC facilities implementing SHARE.

Method

A qualitative descriptive design was adopted to explore the experiences of 18 bereaved family members and 15 managers recruited from the 20 RAC facilities that implemented SHARE between November 2017 and April 2019. Interviews of approximately 60 minutes duration explored psychosocial impacts including satisfaction with care and staff communication skills.

Participants

Bereaved family participants' ages ranged from 40-80 years of age. The majority of interviewees were women, with four out of 18 interviewees being men. Interviewees represented mostly NZ European ethnicity, with two of 18 participants stating their ethnicity as different to NZ European. Manager roles included facility manager (3), clinical manger (9), and clinical coordinator (3). The majority of managers were female (14), under 50 years of age (11), and worked in RAC for more than five years (12). Managers most often reported NZ European ethnicity (4) followed by Indian (3) and Southeast Asian (3). The majority of deceased residents (10) had a diagnosis of dementia and had been ill for a year or less. Quotes from participants were assigned pseudonyms based on a colour (e.g. emerald, garnet etc.).



Dr. Rosemary Frey PhD
@frey_rosemary
r.frey@auckland.ac.nz

Themes

Communication

Managers - keeping family 'in the loop'

In every part of it, you know the family know, because once we identify them, we discuss it and we put, [the person on the register]. You know, not only the resident, but the family. The [PCNS] helped that a lot, you know, for the staff, to make sure that those things, because maybe you know, before that it wasn't really understood by them.

(Aqua)

Family - better staff communication**.**

[The nurse] was always obliging to speak to us. No problem (Teal)

Organisation

Manager – relationship building with staff

Her [PCNS] involvement with the staff, like she'll talk to the staff on the floor and if they're in the office she talks and they've got a relationship now going. And, you know, I'd have her in every week if I could, you know. But they really appreciate it because they can talk you know, openly and, and they feel safe to talk about anything.

(Peach)

Bereaved Family- greater availability of staff

So talk about her care that you observed your Mother getting?

That she was getting? I mean they were wonderful, they were there all the time.

(Violet)

Role of Hospice

Manager – greater hospice input into resident and family care.

The [PCNS] spoke with one of our families she was really upset about her mum's disease condition. And I think after she spoke it helped...and they felt supported so that was good.

(Amber)

And she [hospice nurse] made suggestions [concerning declining resident] the colour had become more pale...we hadn't noticed because we see her every day.

(Peach)

Family- Greater hospice integration and support.

According to Mrs. H, she remember they [PCNS] are coming from Hospice, have talked to her about how they going to care for him [resident]. So those part she was very much involved and have conversation. (Navy)

Challenges

General Practitioner (GP) Relationship. Concerns about GP attitude and communication with family and staff persisted.

Manager-

Was it the GP who did those [palliative care] conversations or didn't it really happen?

No, no.

Didn't happen?

No *(Brown)*

Family-

He was very matter of fact and very - lacking in empathy... he was suggesting that an old sick person that's gonna die is holding up an ambulance that might be more well used somewhere else. So, I guess... I got a bit negative towards him.

(Alba)

Fewer Staff. A private funding model for the facilities in this study created increasing staff shortages creating challenges for the implementation of SHARE.

Manager-

You know we do lose RNs [registered nurses] to the DHB [district health boards], because it's a high rate of pay.

(Heliotrope)

Family -

I know the staff were under a bit of pressure work wise, coz I could tell that they were sometimes. And I could see how tired they looked sometimes. (Crimson)

Conclusion

- After a year of SHARE, the collaboration between hospice and RAC promoted manager and bereaved family member confidence in the care delivered.
- The presence of hospice was felt indirectly by family in the improved communication concerning relatives' changes in condition.
- The register made staff more aware of the need to update family on changes in their relatives' condition.
- GP communication quality and staffing shortages 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.

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2. Froggatt, K., & Payne, S. (2006). A survey of end-of-life care in care homes: issues of definition and practice. Health & Social Care in the Community, 14(4), 341-348.
3. Frey et al. The Supportive Hospice and Aged Residential Exchange (SHARE) programme in New Zealand. Nurse Education in Practice. 2017;25:80-8.