

The Voice of and Interaction with Families and Carers of Residents in Aged Care



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Introduction

Family and carers support is emphasised in Australian National Palliative Care Strategy. An investigation of families' experiences is important when evaluating palliative care interventions in aged care. As part of the evaluation of Comprehensive Palliative Care in Aged Care (CPCiAC) project in South Australia, we developed strategies to seek families' feedback. Findings demonstrate key priority areas in providing support to families and their engagement.

Aim

- To understand families' journey and support they receive from aged care facility
- To present experience of processes and challenges in engaging with families in aged care settings

Method

- Engaged with two families from two separate aged care facilities.
- Tracked families for 6 months
- Conducted two rounds of interviews and completed a diary in between interviews to record activities and interactions with the aged care staff.

When mum died, the chaplain went and cut a big basket of roses. They grabbed a few staff who used to look after mum, and they lined up...it was like a little procession, they said goodbye and put the flowers on...Oh that was nice.



Acknowledgments

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Key Findings

Communication towards end of life is central

- Improves families' engagement in care planning
- Helps to understand the impacts of systems and processes on families
- Requires staff to learn communication skills through education and training

Emotional & spiritual support is highly acknowledged by families

- Helps families during the resident's end of life
 - Supports families during grief and bereavement
- Grief and bereavement support is important*
- Includes risk assessment, provision of resources and referrals to support services

Evaluation learnings

- Inclusion of families' voices enhances the meaning of the evaluation work and a means to measure changes in practice over time
- Engagement with families in evaluation is complex and time-consuming
- Ethical issues around family engagement during a highly emotional time must be considered