

Abstract

Purpose: To address a gap in current evidence by exploring bereaved family perceptions of the transition to a palliative care for their relative in long-term care.

Methods: In-depth interviews were conducted with a convenience sample of twenty-six family members most involved in the care of residents who had died within the last twelve months. Interviews explored observed care, perceptions of staff palliative care knowledge, communication with staff, care planning, and decision-making. The range of responses fit the Donabedian (1966) Health Care model of structure/process/outcome. In the case of long-term care, structure includes staff training; process is the manner of care and outcome would be a 'good' (or bad) death.

Results: There was little evidence that a well-managed transition to a palliative approach to care was being initiated. Key themes included: 1) unrecognised need for transition; 2) information gaps and 3) feeling 'out of the loop' Ten subthemes were also identified.

Implications: Engaging family and relevant internal and external health providers in care planning not only promotes care in line with resident wishes but also assists family bereavement. Results indicate the need for the development of a new collaborative, multidisciplinary model to enhance the delivery of palliative care in long-term care.

Keywords: transition; palliative care; long-term care; aged care; end of life

Family experiences of the transition to palliative care in aged residential care (ARC): A qualitative study

INTRODUCTION

Internationally, long-term care represents an increasingly common site of death for older people (Broad et al., 2013) and in New Zealand, the setting for the current study, as many as one-fifth of all deaths of those over 65 years old occur there (Broad et al., 2013). Long term care, known as aged residential care (ARC) in New Zealand (NZ), includes private hospitals providing 24-hour nursing/medical services, and rest homes that provide support but not 24-hour nursing/medical care (Connolly et al., 2014). In common with the situation internationally, people in NZ are entering ARC with higher levels of dependency (Boyd et al., 2009) complex care requirements (Gomez-Batiste et al., 2014) and with death expected in much shorter periods of time (Currow and Hegarty, 2006). ARC facilities in NZ have been characterised as de facto hospices, in marked contrast to their previous role as rehabilitation centres (Connolly et al., 2014). As such they represent the intersection between continuing care for older people and a palliative approach to care (Froggatt, 2001).

Within the New Zealand context a palliative care can be defined as “care for people of all ages with a life-limiting condition which aims to 1) optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs and 2) support the individual's family, whānau (family group) and other caregivers where needed into bereavement” (Ministry of Health (New Zealand), 2011). Introducing a palliative care is recommended early in the trajectory of a life-limiting illness (Gott et al., 2011). An increasing proportion of ARC residents are experiencing significant levels of palliative care need prior to death (Gott et al., 2012). A well-managed transition to a palliative care includes 1) building consensus within the clinical team as to how resident needs should be addressed; 2) effectively communicating the team consensus to patients and their families; and 3) ensuring patients and family members are offered an opportunity to discuss preferences which are recorded and subsequently acted upon (Department of Health (UK), 2008). Yet is this transition well managed within ARC? Research has indicated that this transition period in ARC is often characterised by indecision or inaction on the part of key decision makers (Travis et al., 2001). Evidence also indicates that staff in ARC may be unprepared for their role in palliative care provision (Marshall et al., 2011) and lack critical palliative care

knowledge (Marshall et al., 2011). Models of palliative care delivery in ARC remain at an early stage of development (Ersek et al., 2014) and more evidence is needed to ensure the needs of residents and their families are met in a timely manner.

The role of the family. Within the ARC setting, family typically play an ongoing role in care (Kellett, 2007) Ensuring they are on the ‘same page’ as clinical staff during the transition to palliative care is crucial. Previous research indicates that staff-family communication is often poor (Bauer, 2003; Weman et al., 2004). This hinders the development of a ‘partnership’ between staff and family which could support good care (Bovenkamp and Trappenburg, 2012), something which may be particularly important at the end of life.

A plethora of international research exists describing the experience of residents, families, and staff at the time of transition into ARC (Ryan and Scullion, 2000; Davies and Nolan, 2003) and documenting patterns of transitions between ARC facilities, hospitals, and home (Callahan et al., 2012). Less is known about the final component of this journey, namely the transition to a palliative approach to care and the resident’s subsequent death. Whilst there has been some research exploring this transition from a staff perspective (Waldrop and Nyquist, 2011; Frey et al., 2016), no previous research could be identified from the family perspective, despite the fact that bereaved family perceptions of care delivered to relatives during their final illness are regarded as an important indicator of the quality of that care (Teno, 2005). It was within this context that the current study sought to explore bereaved family perceptions of the transition to care to incorporate a palliative approach for their relative.

METHODS

This research represents Phase Two of a larger study involving fifty-two facilities that explored palliative and end-of-life care management in ARC (Frey et al., 2015). In-depth interviews with a convenience sample of bereaved family members of residents of nine urban ARC facilities in one district health board were conducted between July 2012 and February 2014. Ethics approval was obtained from the University Human Participants Ethics Committee.

ARC Facilities: Facilities included in this study represent a subsample of the 52 ARC facilities within one urban district health board. Aged residential care (ARC) within this context refers to “care amenities for people who require ongoing assistance with activities of

daily living.”(Phillips et al., 2006, p. 417). In New Zealand, private hospitals deliver twenty-four-hour nursing/medical care, while rest-homes provide lower level or social care but not twenty-four-hour nursing/medical services (Connolly et al., 2014).

Recruitment: Interviewees were recruited from bereaved family members whose relative had died between three and twelve months prior. This time frame was selected was long enough from death to reduce burden for participants, but still enable them to recall details of their relative’s final days (DiBiasio et al., 2015) In order to ensure resident and family confidentiality, potential participants were informed of the study by the Manager and requested to provide permission for contact from the research assistant. Reassurance was provided in the information sheet, making clear that the research was independent of the ARC facility. Contact information was provided for the Health and Disability Services Consumer Advocate should it be required. The research assistant also telephoned the participants one-week post interview to check that the interview did not raise any unresolved concerns.

Over a period of twenty months between 2012-2014 bereaved family members were interviewed concerning their perceptions of care of their relative (between three to twelve months). The interviews were conducted by a trained female social worker (SF) with extensive experience in qualitative data collection, who was not affiliated with the participating facilities or staff. The semi-structured interviews ranged from twenty minutes to one hour. Interviews took place at a location of the interviewees choosing. All interviews were recorded with the permission of participants and transcribed verbatim by a transcriptionist who had signed a confidentiality agreement. Participants were provided the option of reviewing transcripts for accuracy. Two participants requested copies of transcripts, which were returned with minor revisions (e.g., name corrections, grammatical errors).

Questions were developed from a review of the literature as well as previous interview guides (Worth et al., 2009; Csikai and Martin, 2010; Gill et al., 2010). Drawing on Reinke *et al.* (2008) transitions in this research are defined as the experiences that family members viewed as milestones in their relative’s movement from routine care to palliative and end-of-life care. Topics focused on the bereaved person’s transition into palliative care, the communication experienced between family and the residence, and aspects of the physical care, in particular leading to their experience of the palliative care provided (Appendix A).

Analysis: To address issues of rigour and trustworthiness transcripts were read by two of the authors (SF, RF) and core themes were identified. A coding framework was

developed by author consensus and was grounded in the data rather than decided a priori (Thomas, 2006). Themes were only developed in relation to the wider literature following analysis. The range of responses fit the Donabedian (1966) health care model of structure/process/outcome. In the case of long-term care, the structure includes staff training; the process is the manner of care and outcome would be a ‘good’ (or bad) death. This model has been successfully applied by researchers studying end-of-life care in long-term settings (Munn and Zimmerman, 2006; Stewart et al., 1999). Three themes and ten subthemes were derived from the findings. Direct quotations have been selected to illustrate the issues raised by participants, and they are indicative both of typical responses and of the diversity of views obtained. Limited participant information has been associated with relevant quotes in order to maintain bereaved family and decedent resident anonymity.

FINDINGS

Family Member Characteristics

A total of twenty-six people were interviewed concerning their perceptions of care of their recently deceased relative (within twelve months). These twenty-six included eight spouses (four wives and four husbands), eleven daughters, five sons and two sisters.

Table 1 Family Member Characteristics

<i>Family Member Characteristics</i>	Frequency	Percent
<i>Gender</i>		
Male	9	34.6
Female	17	47.2
<i>Age</i>		
25-34	1	3.8
35-54	4	15.3
55 or >	20	76.9
Unspecified	1	3.8
<i>Ethnicity</i>		
New Zealand European	20	76.9
Maori	2	7.6
Chinese	1	3.8
British	3	11.5
<i>Relationship to Resident</i>		
Husband/Wife/Partner	7	26.9
Adult Child	16	61.5
Sister/Brother	2	7.6

Facility Overview

Over half of the nine facilities provided both rest home and hospital level care and most frequently had between thirty-one and sixty beds. One of the nine facilities provided a care pathway (Liverpool Care Pathway) (Ellershaw et al., 1997) for the end of life care (Table 2).

Table 2 *ARC Facility and Resident Characteristics*

	Frequency	Percent
Facilities	9	100
Type		
Rest home	2	22.3
Rest home and hospital	5	55.5
Dementia care only	1	11.1
Rest home hospital and dementia care	1	11.1
Bed Numbers		
20-30 beds	3	33.3
31-60	4	44.4
61 and over	2	22.3
Residents		
Care Pathways		
Liverpool Care Pathway	2	23.0
None		77.0
Gender	26	100.0
Male	9	34.6
Female	17	65.4
Age		
51-61	1	3.8
62 or >	25	84.6
Ethnicity		
New Zealand European	16	61.5
Chinese	1	3.8
British	8	30.7
European	1	3.8
Length of Residence		
0 to 1 month	3	11.5
1.5 months to 1 year	9	34.6
1.5 years to 5 years	12	46.1
5.5 years and over	2	7.6
Primary Diagnosis		
Cancer	7	26.9
Pneumonia	4	15.3
Dementia	8	30.7
Spina Bifida	1	3.8
Cardiac Disease	2	7.6
Inability to Weight-Bear	1	3.8
Old Age	1	3.8
Stroke	1	3.8
Weight Loss	1	3.8
Hospital Admission from ARC		
None	17	65.4
One	6	23.1
Two-Four	3	11.5
Died in Hospital	5	19.2

The workforce was predominantly female (87 percent) worked as health care assistants (HCA's) (60.6 percent) and reported English as a second language (72.6 percent). Ethnic identifications included NZ European, Pacific, Filipino, Indian and Chinese. Staff most frequently reported (29 percent) four to ten years' experience in ARC (see Frey et al. 2015).

Decedent Relatives

Decedent relatives were most often over the age of 62 (84.6 percent) and lived in ARC between one and a half and five years (46.1 percent). The two most common primary diagnoses were dementia (30.7 percent) and cancer (26.9 percent) (Table 2). Family and resident information are presented as aggregate data to protect identities.

Themes

Three themes emerged that characterize participants' perceptions of the transition to a palliative approach to care, namely: 1) unrecognised need for transition (subthemes concerning symptom management and dementia care); 2) information gaps (subthemes include assumptions, tick box exercise, planning, distrust, anxiety, and guilt) and 3) feeling 'out of the loop' (subthemes include out of control, seeking guidance and alternate sources).

Unrecognised need for transition

Participants interviewed reported that health care workers lacked an understanding of the need for a transition to a palliative care. A daughter stated:

'So I did feel for the first time in that last week some inadequacies... I think that it[palliative care skill] was missing'. (daughter)

In particular, issues surrounded symptom management and the care of residents with dementia.

Symptom management: The management of pain, psychosocial distress, and difficulties with eating and drinking emerged as significant issues for respondents. Family members expected nurses, GP's and other staff to take responsibility for keeping symptoms under control. They felt helpless to intervene when they perceived this control to be lacking. The experience of one participant whose wife was diagnosed with breast cancer illustrates these feelings of powerlessness:

‘The day before she died her mouth had got so gummed up, and hard she could not take any of her pills, her painkillers orally...our GP had said to us any problems at all day or night give me a ring. Well, this was Saturday evening, and they refused to call the GP. And they said there’s nobody from [hospice] can come either, so my wife spent that last, oh twelve to fifteen hours in excruciating pain’. (spouse)

Dementia: The needs of residents dying with advanced dementia added to the challenges of palliative care provision. It was the facility’s least educated staff members (health care assistants) who were asked to manage the behavioural and psychological symptoms (e.g. agitation and eating problems). A daughter relayed the following:

Probably three months or so before she died, was that she stopped eating, and she had swallowing problems...She swallowed, and she spat...So in all honesty, I think they were a little slow to act on the medical problems and the lack of eating. (daughter)

Information gaps

Information gaps arose based on assumptions by staff and a protocol driven institutional approach to document resident wishes.

Assumptions: Death is a normal part of working with older people in ARC. This institutional knowledge often resulted in a lack of staff awareness that family does not have that same framework of information and knowledge. It was sometimes taken for granted by staff that family members were already aware of the changes in their relative’s condition. These assumptions prevented discussions of the need for a shift in care goals. Family members often struggled to understand changes in health status based on indirect cues and reported that explicit discussions around prognosis were not initiated with them. For example, a daughter stated that she was surprised to learn that her mother had lost considerable weight in the previous 3-4 months:

The thing was that a chance remark by the nurse, the senior nurse, of well she did lose three kilos over four months...I could not observe the loss of weight...They didn’t sort of say well you expect it; she’s old. It was never mentioned. (daughter)

Assumptions were also made both by staff and families that the residents care wishes were already known (i.e. family member knows him/her). This further contributed to the difficulties for staff in timely transitioning residents to a palliative approach by hampering

an accurate assessment of both the resident's current condition and needs. Adding to the problem families often avoided early discussions as a means of preventing a relative's emotional distress. One participant described her attempt to protect her mother:

We actually avoided that whole conversation...I think the GP mentioned once, would you like to be resuscitated and it upset my mother so much we didn't go back there. She said 'ooh' I'm not ready for talks like that. (daughter)

'Tick Box' Exercise: Within the ARC facilities, palliative care was often viewed by staff from the perspective of the medical model and concerned the direct care of the resident. When they occurred, discussions between staff and family surrounding resident palliative and end-of-life care wishes (e.g. resuscitation status) were protocol driven and usually occurred during resident admission. In other words, discussions were reduced to a tick-box exercise. These discussions often failed to alert families of the need to plan for a transition to a palliative approach. One daughter's experience illustrates this point:

I think we did sit down, and she [manager] sort of said what the options were...And if you'd said to me when she went there that, you know inside a couple of months she'd be gone, I would have thought don't be ridiculous you know. (daughter)

Gaps in information impacted the family in several ways including the prevention of planning, the fostering of distrust and the experience of anxiety and guilt concerning their relatives care:

Planning: Key issues in communication with the staff concerned not being kept up to date on their relative's health, not being informed that their relative was declining in health or near death, and staff when required. Deficiencies in this vital information hindered planning by family members. The following quote illustrates missed opportunities:

I would have loved someone to have sat down with me and said well this is what is going to happen with mum while she is here...It was a missed opportunity because looking back now had I known it was only going to be three months, I would of left work probably and spent that three months with her. (daughter)

Distrust: Lack of needed information about residents' healthcare status fostered a climate of distrust. In particular, GP communication (quality and frequency) had an enormous

impact on the families' perception of care. One son whose mother had been injured from a fall recalled:

He [GP] took two or three days to get there, you know to actually see her... like I say his [GP's] thing was she's dying anyway, so how much poking and prodding do you want, sort of thing...It's not the attitude I would have got from say, my doctor. (son)

Family members sought an empathetic relationship with the GP, yet this was not always achieved. For example, the daughter of an 84-year-old cognitively impaired resident expressed dismay at the clinical coldness displayed by the GP:

He [GP] picked B's [resident] arm up and just let it flop, and he said yes, you can see half of him has had a stroke. And my recommendation is that we don't feed him anymore. And usually, in about three to five days he will be dead...later on, I saw [father] had a tear came down his eye.
(daughter)

Anxiety and guilt: Family members often found themselves in the untenable situation of both grieving for their relative and expected to make care and treatment decisions on their behalf as the end of life approached. Lack of information sometimes led to feelings of anxiety and guilt concerning decisions. The family wanted 'peace of mind'; knowing that 'I did everything I could.' They did not want to be regarded as 'giving up' on their relative. A participant commented: "I have the biggest question mark over for her comfort...I didn't realise what the hyper-aspirating meant, what it was indicating... That's where I needed that information." Feelings of guilt and responsibility were expressed if death occurred following withdrawal of treatments. One spouse talks about feelings of guilt regarding antibiotic withdrawal:

I thought when they wanted to withdraw her from the antibiotics because they were doing no good maybe I shouldn't have said yes... but I had been told it would have made no difference...I still feel guilt about this whole thing, although I know everything was right. (spouse)

'Out of the loop.'

This subtheme describes how a lack of information prevented families from being supported in the decision making process. Three subthemes were identified in relation to the participants' sense of being left out of the loop.

Loss of control: Many relatives found that care decisions were outside their control. In many cases, participants stated that the facility routinely contacted hospice in the final days/weeks of a person's life to help with pain management. The reasoning behind this action was not often communicated well to families:

'The hospice nurses came pretty early on in the piece...So they all knew it was a quick downward slope. But we didn't.' (daughter)

These comments further support the feeling of 'being out of the loop.'

'They had her on a sort of a pump thing. But no one ever said we're going to do this now, you'd just arrive, and it's done. No, when you're asking me about discussions there weren't any.'

(daughter)

Guidance: Families also recounted how they looked to the staff for direction and advice regarding best care options for the resident. When this guidance was not forthcoming, families became anxious and lost confidence in the staff. For example, one daughter desired additional support from staff in understanding the care options for her mother.

'We definitely weren't particularly aware of options. It was because she was a dementia patient...the general hospital was a pretty ghastly sort of option, and that seemed to be the only other option'. (daughter)

Admissions to hospital were for the most part considered to be necessary for acute changes in condition. In some instances, family members felt abandoned to make decisions regarding hospitalisation without professional input. The experience of one daughter illustrates this point:

'She suddenly developed an excruciating headache, and she was really, really distressed... and the staff obviously couldn't cope... Their procedures were really poor...I rang the hospital back and got the Emergency Department and finally talked to a doctor and said, look I'm really, really

worried about her and, you know. So we agreed that I'd take her back in [to the hospital]'

(daughter)

Alternative sources: The need to know what to expect (e.g. anticipated disease progression) emerged frequently across the interviews. Resourcefulness in accessing that information was often necessitated by a lack of sufficient information from staff and GP's. One daughter stated:

'I would come home and get on the internet, what to expect when someone's dying. What are the stages of dying, you know? They [ARC facility] ...could have sat down and said this is what we think is going to happen to your mum....I got a lot more off of the internet than I did from the [ARC facility]'. (daughter)

DISCUSSION

For family members, the transition to palliative care represents a critical point of movement through one set of hopes and expectations to another (Davies et al., 1995). It was evident that the steps needed for a well-managed transition to a palliative approach were lacking for the majority of ARC facilities involved in our study. Whilst prognostication amongst older people, and notably those aged over 85 years who comprise the largest proportion of ARC residents, is recognised as complex (Marengoni et al., 2016), staff sometimes failed to recognise important prognostic indicators. For example, the significance of weight loss (a well-known prognostic indicator for frail older people) (Thomas, 2011). The perception of inadequate care in relation to pain control and insufficient information for relatives during the dying process appears regularly in the literature (Sawyer et al., 2007; Lukas et al., 2013; Savvas and Gibson, 2015) and is mirrored by the perceptions of the participants in this research. Inadequate pain management affects not only the health and quality of life of the patient in pain but also family members, especially if the onset of severe pain occurs during the weekend and at night (Robinson et al., 2014). The impact of observing a relative in pain can be significant for families and can be a source of distress when that pain is left uncontrolled (Robinson et al., 2014). Evidence indicates that increased collaboration between of hospice staff and ARC staff can lead to better pain assessment and management, for ARC residents (Marx, 2007).

Findings also identified deficiencies in other core palliative care clinical skills, notably symptom management for residents with dementia. International research (Brazil et

al., 2012; Goodman et al., 2013) has particularly highlighted the challenges of ensuring adequate symptom management for residents with advanced dementia (van der Steen et al., 2013; Vandervoort et al., 2014). The urgent need to improve palliative care delivery in ARC has been recognised by the Ministry of Health (MOH) and Hospice New Zealand (HNZ). A recent HNZ initiative delivered the education programme 'Fundamentals of palliative care aged residential care' to over 2,000 aged care personnel (Hospice New Zealand, 2012). This education is a generic approach to increasing palliative care knowledge and has improved staff understanding of palliative care needs of older people in aged care (Henning et al., 2015). Although this work represents an important step forward, it is well known that education alone is unlikely to change the practice reality and a more applied multidisciplinary approach is typically needed to enhance clinical care (Harris, 2006).

Palliative care competence is also intimately linked to clear communication. As the number of people requiring ARC rises, there is a concomitant shortfall of workers to meet this need (Badkar et al., 2009). This gap is increasingly being met by recent migrants of culturally and linguistically diverse (CaLD) backgrounds (Fine and Mitchell, 2007). Misunderstandings based on language and cultural differences can impact on care delivery (Crichton and O'Neill, 2016). However, any solution to improve communication must address not only English language proficiency but also include an understanding of how cultural beliefs and values (e.g. beliefs about ageing, death, dying, etc.) influence communication within the workplace (Nichols et al., 2015). Results demonstrate the urgent need for intercultural awareness education and training as a key component of any education package.

As our results demonstrate, communication may also be thwarted by some health professionals' ageist attitudes and a lack of compassion for older adults (Evans et al., 2012) factors previously reported within the ARC setting (Nussbaum et al., 2001; Dobbs et al., 2008). Ageist behaviours (e.g. patronizing language styles, differential treatment), result in potentially adverse effects on the physical and mental health of both residents and their families (Haug, 1994; Nussbaum et al., 2005). Introduction of content emphasizing communication with older patients as well as the perils of ageism in the medical setting to health professional training and continuing education courses may serve to reduce negative stereotypes and facilitate communication on a more "consultative and participatory basis" (Edward and Giles, 1998, p. 3).

Death is a natural part of life and needs to be viewed in a social context rather than a medical one. The goal of delivering 'family centered' care reflects the sentiment that the

ARC resident is not treated in isolation and the family is not merely a passive recipient of services but an active participant in decision making (Nolan and Dellasega, 1999). It was apparent that staff members were failing to communicate information about residents' likely prognosis to family members, confirming previous research conducted both in other settings (Anderson et al., 2013) and in an ARC context (Towsley et al., 2015). Early communication, exploration of resident wishes, and identification of an advocate have been identified as key to good palliative care within ARC settings, particularly for residents with dementia (Goodman et al., 2013). Greater attention to the frequency and type of communication is required, alongside recognition of the need to respond to family member's concerns as these evolve (Schofield et al., 2006). Family members also should be included in decisions concerning the introduction of specialist palliative care such as hospice. Evidence suggests that the introduction of case conferencing may assist families with end of life decision making (Phillips et al., 2013). Engaging family and relevant internal and external health providers in care planning not only promotes care in line with resident wishes but also assists family bereavement. Feeling as though care deviated from a relative's wishes is a known predictor of prolonged and complicated grief (Neimeyer and Burke, 2012; Martz and Morse, 2016).

The partnership between the facilities, the family and internal and external care providers can contribute to good care when the resident's health status is more stable. The challenge now is to ensure this partnership becomes central to care delivery during the transition to palliative care. As a step toward achieving this goal, results of the current study have supported the development of a new collaborative model to enhance the delivery of palliative care through increased integration between aged residential care providers and hospices. The new model currently under evaluation in 20 facilities within the district health board (including ARC facilities in the current study), will provide opportunities for mutual learning and acknowledgment of specialist knowledge in both gerontology and palliative care.

As in all research, some limitations must be noted. The retrospective nature of this study means that direct resident experiences were absent. Issues surrounding the validity of proxy interviews have been well discussed in the literature (e.g. Addington-Hall and McPherson, 2001). Although family members tend to rate resident symptoms more severely, resident and family agreement is high in relation to service use and evaluation (Addington-Hall and McPherson, 2001). The participants were interviewed up to one year after the resident death. Previous research has indicated a similarity of responses between participants

recruited early or later after bereavement (Lynn et al., 1997). Finally, the study was conducted in a small number of ARC facilities in New Zealand. However, the findings have strong resonance with international research conducted in ARC settings (Thompson et al., 2008; Hennings et al., 2010; Stajduhar et al., 2011) Descriptions of the context, the residents, the bereaved family members and the use of quotes may further assist the reader in reaching their own conclusions on the transferability of the findings (Tong et al., 2007).

Conclusion

Findings indicate that a managed transition to a palliative care for ARC residents is often lacking. As the role of ARC changes from rehabilitative to 'de facto hospice' a new collaborative and interdisciplinary model of care is needed to address the transition to the end of life. In short, a 'continuum of care' needs to be established within ARC (Oliver and Oliver, 2011). Residents and their families should expect that their care choices do not end with entry to ARC, but rather end with a transition to the last twelve months in an environment with a plan of care that is appropriate for the end of life.

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SUPPLEMENTARY

Appendix A

Table 1

Interview Guide Topics and Questions

Section	Topic	Sample Question
1	General Information	<ol style="list-style-type: none">1. Please describe your experiences when [name] first moved into an ARC facility?<ol style="list-style-type: none">i. How long was [name] resident in the facility prior to death?ii. What was the main reason for [name]'s move to this facility?2. How did your role change when [name] moved into this facility?3. What role did cultural traditions play for your family in this situation?4. Could you please tell me about the circumstances surrounding [name]'s death?
2	Communication and Family Care	<ol style="list-style-type: none">1. Who did you contact at the ARC facility regarding [name]'s care?2. Was this the healthcare professional most important in [name]'s care?<ol style="list-style-type: none">i. How would you describe [name] relationship with [professional]?3. Did anyone in the facility suggest support services to you as a family member?<ol style="list-style-type: none">i. If yes, please describe.ii. If no, why not?4. Was information provided by ARC staff clear? Why/Why not?<ol style="list-style-type: none">i. Can you recall any moments when you may have desired more information?5. Were you notified about changes in [name]'s condition?<ol style="list-style-type: none">i. If yes, would you be able to describe how you were notified about changes in care?ii. If no, why do you think you were not notified
3	Advance Care Planning	<ol style="list-style-type: none">1. What did you know about [name]'s wishes regarding end-of-life treatment?2. To the best of your knowledge, were these ever discussed with staff members?<ol style="list-style-type: none">a. If yes, with whom?b. If not, why do you think this was?
4	Staffing	<ol style="list-style-type: none">1. What were your expectations of care from staff members in [name]'s ARC facility?2. How confident were you that staff was able to recognize that [name] was dying?3. How confident were you that they were able to deal with [name]'s needs at this stage of life?4. Was staff available to [name] and to your family? (Prompt: Physicians, nurses, other staff?)5. How did you feel staffing could have been improved in

[name]'s ARC facility?

Table 1 (continued)

Interview Guide Topics and Questions

5	Transitions in Care	<ol style="list-style-type: none">1. What does the term palliative care mean to you (Prompt previous knowledge)?2. Where do you feel death should ideally occur? Why?3. Was [name] transferred to hospital at any stage leading up to their death?4. If yes, whose idea was it to transfer [name]?5. If professionals, why do you think this was done? Did you agree?6. If family, what were the main reasons for this decision?7. Did healthcare professionals recommend transfer for [name]?8. Could you please explain the circumstances surrounding this?9. Which services did [name] utilise?10. Were you satisfied with [name] treatment? Why? /Why not?12. What did you see as the benefits of the transfer?13. Were there any disadvantages?14. What about the experience could have been improved?15. If no:16. Why wasn't [name] hospitalised?17. Are there any circumstances in which you would have chosen to use hospital services?18. Was [name] transferred to any other care setting leading up to their death? [repeat as for Q6/3]
6	Support/Closure	What sources of support do you think you might have benefited from but haven't received since the death of (deceased relative's name)?
7	Debrief	Additional sources of support were offered at the end of each interview (Consumer Advocate- Health and Disability Services). These are detailed on the participant information sheet.