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## Necessary but Not Yet Sufficient: Aged Residential Care (ARC) Staff Perceptions of Palliative Care Communication, Education and Delivery

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**Background:** The number of persons dying in aged residential care (ARC) facilities continues to increase. Yet research indicates that palliative care delivery in ARC may still be suboptimal. To explore this issue, staff perceptions of the quality of palliative and end-of-life care communication, education and delivery were surveyed in 52 ARC facilities in one urban district health board in New Zealand.

**Design:** A survey was conducted with clinical staff members (n = 431) from 52 residential care facilities within one urban district health board. The questionnaire included both closed (dichotomous, multiple-choice, scaled) and open-ended responses.

**Results:** Participants reported confidence that they were part of a team that could care for the needs of end-of-life residents (43.6%). However 32% of participants felt their work was complicated by their co-workers' opinions about the care of end-of-life residents. Perceived areas for improvement in resident care were the delivery of basic cares (11.8%), information access/communication (10.2%) and psycho-social support for the residents (8.9%). Thematic analysis of open-ended questions provided further description for the quantitative results.

**Conclusion:** Despite surface-level reported staff confidence, the study reveals continued challenges to palliative and end-of-life care delivery in ARC as well as an ongoing need for staff education.. Results suggest the need to develop an end-of-life model of care which includes prior discussion of goals of care with residents or their representatives.

## **INTRODUCTION**

As populations age, increasing numbers of people are spending the last months or years of their lives in aged residential care (ARC) facilities with chronic and progressive conditions.(1) Therefore, palliative and end-of-life (EOL) care is a significant component of work for ARC staff.(2) However, there is mounting evidence to demonstrate that palliative care delivery in ARC may be suboptimal.(3) For example, a number of international studies have examined ARC staff experiences and needs in providing care to residents with palliative care needs' (4, 5) and all report shortfalls in clinical staff training and significant gaps in knowledge of palliative care, including the topic of palliative care communication.(6) Effective communication is a key component of both staff palliative care training.(7) and family understanding.(8) Results of previous international research examining the reasons why ARC residents are inappropriately admitted to acute hospitals included the finding of insufficient communication between health professionals, residential care staff, and residents and their families.(9) Similar findings have been reported in New Zealand,(10) the setting for the study reported in this paper.

## **THE NEW ZEALAND CONTEXT**

An estimated 28,000 people over 65 live in ARC facilities in New Zealand.(11) of whom one third are over the age of 85.(12) As in other industrialised societies, a great many of these people will enter ARC facilities presenting with multiple comorbidities (e.g. cardiovascular diseases, stroke, some cancers including prostate cancer, and neurological conditions, such as Parkinson's disease and dementias)(4) and often at a later stage of illness, thereby demanding a higher level of skill from staff .(5) ARC mortality in New Zealand is high.(13) Indeed ARC facilities in New Zealand have been characterised as 'de facto hospices', in contrast to their previous role as rehabilitation centres.(6) In recognition of the important role played by ARC in end-of-life care, education initiatives have been implemented (e.g. Fundamentals of Palliative Care)(14) and integrated care pathways have been trialled (e.g. Liverpool Care Pathway).(15) However ARC staff may still be unprepared for their role in palliative and end-of -life care provision. A post Liverpool Care Pathway (LCP) implementation survey by Clark et al.(15) at three ARC facilities reported increased staff confidence regarding their care skills in palliative and EOL care, including aspects of communication, teamwork and use of documentation. However a need for further education and continued barriers to palliative care delivery related to the organisational environment were noted in that study.(15) Research by Fryer et al. (Fryer S, Gott M., & Bellamy G., 2015) further identified that health care assistants (HCA's) (who provide the majority of direct care to EOL residents) lack the communication skills needed to address residents' concerns about death and dying.

The aim of the present study was to describe staff perceptions of the quality of palliative care communication, education and delivery in ARC settings to inform future strategies for enhancing quality of care for ARC residents with palliative and end-of-life care needs.

## **RESEARCH DESIGN AND METHODS**

A descriptive cross-sectional design was employed utilising a survey of clinical staff in 52 ARC facilities in one urban district health board. Ethics approval was obtained from the University of Auckland Human Participants Ethics Committee (ref # 8742).

### **Definitions**

Within the context of this study the following definitions have been adopted:

Palliative care is defined as “care for people of all ages with a life-limiting condition”(16)

End-of-life according to the Gold Standards Framework (GSF) Prognostic Indicator guidance refers to patients expected to die in the next twelve months.(17)

Aged residential care (ARC) refers to “care amenities for people who require ongoing assistance with activities of daily living.”(18), <sup>p. 417</sup> In New Zealand, private hospitals deliver 24-hour nursing/medical care, while rest-homes provide lower level or social care but not 24-hour nursing/medical services.(6)

### **Data Collection and Analysis**

A survey was conducted with clinical staff members (n = 431) from 52 ARC facilities within one urban District Health Board conducted between Nov 2012 and Feb 2013. The District Health Board serves 468,000 people overall and 27 percent of that number live in ARC. The number of clinical staff across the 52 facilities as reported by the facility managers totalled 1280. One thousand questionnaires were distributed and a 43% response rate achieved.

The survey tool was adapted from a questionnaire of palliative care education needs administered to medical and nursing staff in one acute hospital in New Zealand.(19) Questionnaire topics included: formal palliative care training, experience in palliative care delivery and palliative care communication. Full methodological details are described elsewhere.(20) Quantitative data were coded into SPSS 20. Responses to closed-ended survey questions are reported as descriptive (frequencies, mean, standard deviation) and inferential statistics appropriate to level of measurement (*t* test, ANOVA). Respondents to an open-ended question dealing with thoughts and concerns related to palliative and EOL care represent a subset of survey respondents (35%). According to O’Cathain and Thomas (21) “comments from a subset of responders are still valuable data even when they do not represent the entire sample (p. 25).” There was no significant difference between responders and non-responders to the open ended question ( $p > .05$ ) based on gender, age group or role in the facility. Directive content analysis was selected as the method of analysis.(22) This involved the development of coding categories informed by the three topic areas targeted in the questionnaire. Quotes were selected to illustrate and further elaborate responses to the closed questions. Written responses to the open-ended question ranged from one to 39 words in length and were coded individually. Minimal descriptive details have been associated with the quotations to protect participant identity.

## **RESULTS**

### **Demographic Overview**

Staff participants were most often female (87.5%) worked as health care assistants (HCA's) (60.6%) and reported English as a second language (72.6%) . HCA's predominantly listed Pacific (48%) or 'Other' (42.2%) (E.g. Filipino, Indian and Chinese) as their ethnic identification, while nurses (RN, EN, Charge Nurse/ Senior Nurse) primarily reported 'Other' (61.5%) (E.g. Filipino, Indian, Chinese and Asian unspecified). One hundred and nine participants (25.3%) reported a Bachelor's degree or higher, while 64 (14.8%) reported a Certificate as the educational qualification responsible for their employment in their current position. Participants most frequently reported (29%) 4 to 10 years' experience in ARC (Table 1).

Table 1  
Demographic Characteristics

<b>Staff Participant Characteristics</b>		Frequency	Percent <sup>a</sup>
<b>Gender</b>	<i>n</i> = 419		
Male		42	9.7
Female		377	87.5
<b>Age</b>	<i>n</i> = 410		
17-25		43	10.0
26-35		119	27.6
36-45		83	19.3
46-55		102	23.7
56-65		54	12.5
65+		9	2.1
<b>English First Language</b>	<i>n</i> = 417		
Yes		104	24.1
No		313	72.6
<b>Ethnicity</b>	<i>n</i> = 416		
NZ European		60	13.9
Māori		9	2.1
Pacific		158	36.7
Other ( <i>incl. Asian, Southeast Asian, African, Middle Eastern, European, British, North American and Australian</i> )		189	43.9
<b>Role</b>	<i>n</i> = 417		
Health Care Assistant		261	60.6
Registered Nurse		84	19.5
Other (e.g. physiotherapist, diversional therapist)		25	5.8
Enrolled Nurse		16	3.7
Clinical Manager		11	2.6
Care Coordinator		11	2.6
Charge Nurse/Senior Nurse		9	2.1
<b>Educational Qualification</b>	<i>n</i> = 241		
Bachelor's degree or higher		109	25.3
Diploma		47	10.9
Certificate Course/Work Training		64	14.8
None		21	4.8
<b>Years in RAC</b>	<i>n</i> = 394		
< 12 months		40	9.3
1-3 years		111	25.8
4-10 years		125	29.0
10 + years		118	27.4

<sup>a</sup>Refers to percentages of the whole group (*n* = 431) and may not sum to 100% if respondents did not report on a specific question or because of rounding.

### **End-of-Life Care Experience and Education**

Staff members most frequently reported (25.3%) that between 51 to 75 percent of their time was spent caring for residents who were in the last 12 months of life. The proportion of residents estimated to be in the last 12 months of life was most often reported (23.9%) to range between 1 and 25 percent. In terms of clinical experience, participants most frequently reported (43%) observing EOL care more than three times in the past year , while 139 (32.3%) had delivered bad news more than three times in the past year (Table 2).

Table 2 Palliative Care Delivery (frequency and percent of responses)

	Frequency	Percent <sup>a</sup>
<i>Percentage of time caring for residents in the last 12 months of life</i> <i>n = 366</i>		
none	12	2.8
1 -25%	66	15.3
26-50%	86	20.0
51- 75%	109	25.3
76 – 100%	93	21.6
<i>Proportion of residents eligible for end-of-life care</i> <i>n = 320</i>		
none	12	2.8
1- 25%	103	23.9
26-50%	68	15.8
51-75%	74	17.2
76-100%	63	14.6
<i>Overall quality of care of people who died in your facility</i> <i>n = 269</i>		
Poor	1	0.2
Fair	16	3.7
Good	74	17.2
Very good	164	38.1
Excellent	144	33.4
Don't know	14	3.2
<i>Frequency of observing EOL care in the last year</i> <i>n = 396</i>		
Never	175	40.6
1-3 times	186	43.2
> 3 times		
<i>Frequency of delivering bad news in the past year</i> <i>n = 395</i>		
Never	129	29.9
1-3 times	139	32.3
> 3 times		
<i>Hospital Transfer Reasons (multiple response)</i> <i>n = 379</i>		
Acute episode of illness	215	46.2
Symptom control	108	23.2
Injury	103	22.2
Other ( incl. ageing, disease progression, need hospital level care)	39	8.4
<i>Who makes the decision for transfer? (multiple response)</i> <i>n = 413</i>		
Physician (GP)	303	51.8
Family	172	29.4
Other (incl. RN, Needs Assessor, Manager, Patient, EPOA)	110	18.8
<i>Areas of resident care in need of improvement (multiple response)</i> <i>n = 381</i>		
Basic cares	45	11.8
Information/communication	39	10.2
Psychosocial support - resident	34	8.9
Comfort cares (palliative care/Liverpool Care Pathway)	32	8.4
Family support	30	7.9
Resident – caregiver time	25	6.6
Equipment (unspecified)	22	5.8
Facility management	20	5.2
Pain management	20	5.2
Religious/pastoral care	19	5.0
Medical care (unspecified)	19	5.0
Interpreter	18	4.7
Education/training	18	4.7
After death training/support	14	3.7
Medications/medical information	8	2.1
Physician contact	7	1.8
Staff emotional support	6	1.6
Dementia care	3	0.8
Hospice support	2	0.5

An HCA spoke about her long years of experience working with residents at the EOL:

Because of the experience I have working as a health care assistant, I love caring for dying residents.

(HCA, 10 + yrs. in ARC)

There was a perception however, that some doctors did not possess adequate palliative care skills and knowledge. A charge nurse drew on her long experience in aged care for the following observation:

I have found that many GP's lack the confidence in making the appropriate decisions re medications.

(Charge Nurse, 10+ yrs. in ARC)

Only 199 (46.2%) of staff participants reported undertaking formal palliative care education courses. The number of participants who reported formal palliative care education varied significantly by role ( $t(409) = 15.64, p = .000$ ) with health care assistants (HCA's) less likely to have engaged in formal education in comparison to either nursing or allied health professionals.

A majority of the participants (80.5%) however indicated that they would like formal palliative care education. A health care assistant further elaborated that this training should be kept up to date:

All staff either HCA or Nurses need to undergo palliative care training (theory and practically hands on). Training to be reviewed every 2 years' time.

(HCA, less than 1 yr. in ARC)

Those participants who had taken educational courses most frequently reported that they lasted for durations of one day or less (72.5%). Of those who reported formal palliative care training 42.7 % agreed<sup>1</sup> with the statement that training had equipped them with the necessary skills and knowledge to care for a person at the end of life. They also perceived increased self-confidence in the delivery of end of life care (40.6%) and increased job satisfaction (39.9%). One HCA, who had worked in the sector over ten years, commented:

Carers can only perform if they know or are skilled in the tasks given to them.

(HCA, 1-3 yrs. in ARC)

### **Palliative Care Supports**

Staff members reported their frequency of access to palliative care supports. Of the 278 responses, the most frequently accessed support was training in the care of patients and families at the end of life (19%) followed by specialist knowledge and support through hospice (11.1%) (Figure 1). Of those participants requesting additional supports (n = 61), the most frequent response was specialist support from hospice (16%) (Figure 2).

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<sup>1</sup> Represents combined agreed and strongly agreed percentages.

[Figure 1]

[Figure 2]

### **The ARC Environment: Fostering Palliative Care Communication**

Participants responded to 12 items (1 strongly disagree to 5 strongly agree) about the quality of the work environment for facilitating palliative care communication and delivery. Overall the staff were positive in their assessment of the both the communication quality and supports in place to facilitate care. Participants reported confidence that they were part of a team that could care for the needs of EOL residents (43.6%). Participants (39.2%) reported that they were able to discuss death and dying with relatives or carers (Table 3).

Table 3 Palliative Care Communication, Support and Education (n = 431)

Topic/Questions	Responses as a Percentage					
	<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Neither Agree nor Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>	<i>Not Applicable</i>
<b><i>Palliative Care Communication &amp; Care</i></b>						
It is possible to spend all the time needed for any task with the dying resident	7.4	26.2	19.0	29.0	11.6	2.3
Managers/senior staff are on hand to answer questions about the dying resident	3.9	5.8	10.0	46.9	26.2	2.3
I feel able to discuss death and dying with residents	7.4	20.0	18.3	33.4	10.7	4.4
Work is complicated by different opinions from supervisors/co-workers on the care of residents with palliative care needs	7.4	20.4	17.6	32.5	13.5	2.8
I feel able to discuss death and dying with relatives/carers	5.3	18.1	12.3	39.2	13.9	3.7
Questions which residents ask about their disease, death or dying needs are always referred to the Dr. or Manager in the first instance	5.3	10.0	10.9	37.8	25.3	4.9
<b><i>Support</i></b>						
I feel confident that I am part of a care team that can care for the needs of a resident who is at the end of life without the need for hospitalisation	2.1	8.4	8.8	43.6	29.9	1.9
I feel that my contributions to the palliative care needs of residents are valued	2.6	4.9	8.4	48.3	29.2	2.3
Staff are provided with emotional support from Managers and colleagues regarding working with dying residents	4.2	12.3	16.2	41.1	18.6	2.6
I feel that I am able to utilize all my skills in palliative and end-of-life care	1.6	6.3	10.9	47.3	26.7	2.8
<b><i>Palliative Care Education Access</i></b>						
Staff have access to training in recognizing and managing end-of-life care needs in residents	3.5	9.3	13.2	45.7	20.6	2.6
Staff have access to training in the care 'after death' of the dying patient	3.5	14.4	16.0	40.1	16.5	3.5
<b><i>Perceived Education Impact (n = 199)</i></b>						
Training has equipped me with the necessary skills and knowledge to care for a person at the end of life	2.5	.5	2.5	33.2	38.2	2.0
As a result of training my self-confidence to care for persons at the end of life has increased	1.2	.0	3.2	19.3	21.3	2.3
As a result of training my job satisfaction has increased	1.2	.2	3.9	20.6	19.3	2.1

Yet open-ended comments sometimes contradicted this reported confidence. An enrolled nurse (EN) who had formal palliative care education made the following recommendation:

Terminally ill residents may need preparation on death and end of life care with their family members (hand-outs or meetings with carers). Staff need training on a good approach about the topic. (EN, 1-3 yrs. in ARC)

Turning to intra-staff communication, 140 (32.5%) of the participants agreed with the statement that “work was complicated by the opinions of co-workers about the care of residents with palliative care needs.” Opinion was also divided with regard to adequate time available to spend with residents: 113 (26.2%) disagreed while 125 (29%) agreed (Table 3). One HCA summed up the time problem succinctly:

Less multi-task and more hands on with clients. (HCA, 10+ yrs. in ARC)

Individual items concerning palliative care communication were combined to create a measure of perceived openness of the ARC work environment for palliative care communication. Higher scores represented a greater perceived openness for palliative care communication (range 13-65) (20). There was a significant difference in perceived openness of the environment based on whether or not the participant had reported engaging in formal palliative care education ( $t(288) = 2.82, p = .005$ ). Staff who reported formal palliative care education recorded a higher mean scale score ( $\bar{x} = 47.27, SD = 8.06$ ) in comparison to staff with no formal palliative care education ( $\bar{x} = 44.94, SD = 6.28$ ). In other words staff with formal palliative care education perceived a more open palliative care communication environment in comparison to those without formal palliative care training.

Previous experience in observing end of life care also impacted on perceptions of the work environment for palliative care communication facilitation. A one-way analysis of variance demonstrated that the effect of experience was significant,  $F(2,289) = 3.27, p = .039$ . A Tukey post-hoc test revealed that perceptions differed significantly for those participants who had never observed EOL care ( $\bar{x} = 43.19 \pm 6.8$  min,  $p = .04$ ) compared to those who had done so more than three times ( $47.06 \pm 7.0$  min).<sup>2</sup> Thus experience in EOL care (EOL observed > 3 times) led to increased perceptions of a work environment facilitative of palliative care communication.

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<sup>2</sup> Those participants who had observed EOL care one to three times did not differ significantly from those who had never observed EOL care ( $p = .230$ ) or done so over three times ( $p = .335$ ).

## Reasons for Acute Hospital Admissions

Staff also reported on the reasons for resident acute hospital admission. The most frequent answer to this multiple response question was an acute episode of illness (46.2%) followed by symptom control (23.2%). However, one HCA concluded that the absence of early investigation and intervention may have been associated with some hospitalisations:

Not enough attention given at time when they need it.

(HCA, unknown yrs. in ARC)

Participants also mentioned resource limitations as a contributing factor to hospital transfers. A clinical manager made the following observation:

If rest homes were to have registered staff on at night this would make a difference in how we care for palliative residents. It is a shame that we have to move ill people because we can't meet their needs.

(Clinical Manager, 10+ yrs. in ARC)

Participants listed physicians (GP) (70.5%) followed by family members (29.4%) as the persons most often responsible for making the decision for a resident's hospital admission. Hospital admissions were sometimes perceived to be at the insistence of a close friend or family member acting under an enduring power of attorney (EPOA). A registered nurse commented:

Sometimes...I know transferring a resident to the hospital is not going to help, but at the insistence of the EPOA I have to do it. There should be more public forums for people to realise that transferring at times does more harm than good and [it is] a wastage of time!

(RN, 4-10 yrs. in ARC)

## Recommendations

Overall, staff most often (38.1%) rated the care of residents who had died in the facility as 'very good' (n= 164), yet they were also aware of the constraints of the ARC environment. Included among the 204 responses and 18 topics suggested by participants the three most frequently reported areas for improvement in resident care within the facility were the delivery of basic cares (11.8%), information access/communication (10.2%) and psycho-social support for the resident (8.9%) (Table 2). In terms of external psycho-social support, participants envisioned improvements that could result from greater involvement of families. One HCA noted her concern about absent families:

Some of the residents with lots of relatives were supportive, but some residents with no one around.

(HCA, 10+ yrs. in ARC)

A healthcare assistant summed up her thoughts for improving palliative and EOL care in ARC as follows:

To care for someone at the end of life is so very important to me....Every bit of training, understanding and compassion is a must. We are dealing with human beings who deserve to be treated with the utmost respect and dignity. Education and communication [skills] should be held by all in this field.

(HCA, 1-3 yrs. in ARC)

## DISCUSSION

This paper has identified ongoing issues in the provision of palliative care within the aged residential care setting. Notwithstanding expressed staff confidence, the results reveal continued shortfalls in palliative care and EOL knowledge, communication and delivery. (2) Internationally, education has been seen as the most effective way of addressing deficiencies in palliative care provision in this setting. (18) Indeed, results of the present study indicated greater perceived openness of communication among staff with formal palliative care education. However is this confidence reflected in action? Education initiatives developed to date have focused on short training programmes emphasising didactic methods. (23) New Zealand is following this trend (e.g. Fundamentals of Palliative Care). (14) Nevertheless, translation of educational interventions to the real-life setting of ARC remains a major challenge. (24) As research on the negative impact of burnout on education uptake has demonstrated, one reason for the failure of some of these interventions to promote sustainable change has been a lack of consideration of organizational factors. (20) These conditions (time pressures, low staffing levels) create barriers to the application of new knowledge. (24) Our findings therefore add to the growing body of evidence indicating a need to develop more effective models of palliative and end of life care education in ARC settings.

Despite expressed confidence in being a member of a team capable of delivering care at the EOL, gaps in communication were evident in the results. Poor communication creates situations in which crucial information is not exchanged between staff, residents and families. (25) Lack of appropriate information exchange adversely affects decision-making, care planning and ultimately resident wellbeing. (26) In line with Marshall et al. the results demonstrate issues with intra-staff communication. (2) Coordination of resident care through teamwork is integral to effective palliative care delivery and relies on open communication. (2)

Inadequate care planning, and communication are factors noted in previous research as influencing the decision to transfer ARC residents to the acute setting. (27) Within ARC, a skilled workforce improves resident outcomes, for example by reducing acute hospitalisations which are potentially hazardous for frail older people. (28) Similar to results by Hanger et al (29) the majority of the acute admissions were reported to be due to sudden changes in condition. Failure to respond to these changes would be inappropriate and could indicate poor care. (30) While it is acknowledged that some hospital admissions are necessary for acute and specialist care, previous research also suggests that better preventive care and emphasis on managing acute illness within ARC improves resident health outcomes. (31) and may reduce unplanned hospital admissions. (32) Linked to this point are reported difficulties among generalist's in identifying and managing patients' palliative care

needs.(33) This is particularly important given that GP's were listed most frequently by staff as the decision-maker in terms of hospital admissions.

In addition to increased education, the adoption of an end-of-life model of care may also serve to reduce the hospitalisation of residents.(34) This model would include prior discussion of goals of care with residents or their representatives (EPOA). Informed discussion, may lead some residents or their delegated representatives to opt to focus on quality of life and symptom management rather than hospitalisation.(35, 36)

As in all research, some limitations must be noted. Survey respondents represent a convenience sample, and therefore non-randomised and non-uniform across the included facilities. It is also unclear whether staff members' knowledge and confidence in their abilities translated into actual palliative care expertise, as the research did not include observations of staff in clinical practice. Finally, this study was conducted within one urban district health board, which may limit generalizability of its findings, and therefore further research is needed to examine trends nationally.

## **CONCLUSION**

Despite surface-level reported staff confidence, a closer look at the results reveals continued challenges to palliative and EOL care delivery in ARC, as well as an ongoing need for staff palliative care educational interventions that are contextually appropriate, and sustainable.

Providing palliative care education to staff is a necessary, but not sufficient, condition to improve the care of residents. Such interventions must form part of a larger model of EOL care in ARC that supports improved communication among the healthcare team, residents and families so that the palliative and EOL needs of residents are genuinely met.

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**DISCLOSURE STATEMENT**

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