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Exploring the impact of a Palliative Care Education Programme

“What the participants had to say.”

Claire Hatherell

RN. DN Cert. BSc(Hons). PG Diploma(HSc-Advanced Nursing).

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Abstract

Background: The numbers of older adults are increasing, in developed countries many live and die in Residential Aged Care facilities with New Zealand having the highest percentage (34%). The characteristics of residents entering Residential Aged Care facilities are changing; they are older, have multiple co-morbidities and their survival is shorter. The Palliative Care Approach is seen therefore as having increasing relevance in this care setting but the Palliative Care needs of residents and their families/whānau are not always recognised by staff. Staff have experience of death and dying but lack formal education and training in Palliative and End of Life Care.

Aim: The aim of this is to explore the impact of a Palliative Care Education Programme delivered to all staff in Residential Aged Care facilities in the Waitemata District Health Board, New Zealand. The education programme aimed to raise awareness of the Palliative Care Approach and increase staffs' confidence through building on their existing knowledge and skills.

Method: A qualitative research method was used. Focus groups were held in 5 Residential Aged Care facilities who had participated in 4 to 6 sessions of the WDHB Palliative Care Education Programme during 2012.

Findings: Participation in the education had affirmed and validated staffs' existing knowledge and skills. Following attendance at the education, staff reported new knowledge and a deeper understanding of the holistic nature of Palliative Care. The education had made them think differently about their residents and had raised awareness of cultural considerations of both staff and residents. Staff recognised the benefit of the Palliative Approach for other residents that it was not restricted to end of life care. Most noticeable was the acknowledgement from staff of the need to involve the family/whānau in their resident's care. Staff spoke of an increased confidence, improved assessment and communication skills and being less fearful to engage directly with dying residents and their family/whānau. There was an attitude and behaviour shift with staff reporting that their practice had changed.

Implications from this research are that education about palliative care, delivered in this way, is acceptable and appears to have resulted in attitudinal shifts. Quality of care is likely to improve as a result.

Dedication

This thesis is dedicated to two very special people. Winifred Mellin Beesley (affectionately known as Aunty Win) who taught me much about coping with ill health and about living with loss and grief. She also inspired my literary skills with her love of the English (or should I say Welsh!) language. I would also like to dedicate this thesis to my husband Andy, for his constant love, patience and support. Diolch yn fawr, Thank you very much.

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1. LITERATURE REVIEW

The literature comprised of pre-dominantly peer reviewed journals and academic books from the University of Auckland libraries. The literature search was conducted using the electronic databases of the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, EBSCO, Internurse.com, Google Scholar and PubMed. Keywords used were Palliative Care, Older adult, Nursing/Care homes, Residential Aged Care, Education, Evaluation/Outcome measures. The search was limited to articles in English.

Rationale

This literature review considers the background and context to the thesis, residential aged care, palliative care and quality of care for people who are dying. The population is changing as is the place of death. In New Zealand for older adults (65 years and over), 34% die in Residential Aged Care facilities, the highest figure of the world's developing countries (Broad et al., 2011). The review then poses several questions which are answered by systematically searching the literature: how are staff managing to care for residents whose acuity levels are increasing? What do staff themselves feel they need with regards education and support? The existing Palliative Care education programmes are reviewed along with how they were delivered and how effectiveness had been measured, particularly in relation to improved care outcomes. The development of a Residential Aged Care Link Nurse programme of regular education and support meetings is outlined. These Link Nurses represent organisations whose work culture dictates how Palliative Care is delivered. I am also working alongside and caring for people from a diverse range of ethnicities and cultural backgrounds. The Palliative Care approach is a Western concept and may not always align with everyone's beliefs and values. The literature review is concluded by discussing the role of the Palliative Care Link Nurse and the influences of culture and ethnicity in relation to Palliative Care.

Deaths

It is estimated that by 2030, global deaths will number 74 million (Gomes and Higginson, 2008) and that a significant proportion of these will occur in older adults with chronic

diseases. The number of older adults (65 years and over) in developing countries is increasing and of particular concern is the increase in the number of those aged 85 years and above who will account for nearly half of all deaths by 2030.

Older Adults - place of death

Place of care for the older adult has seen a shift away from home at end of life due to a variety of influencing factors (Gomes and Higginson, 2008). There is an increasing shortage in the availability of family carers who might be in a position to offer help. The present economic climate drives the need for a more mobile workforce which in turn has caused family dispersion and placed upon them greater financial burden. Other factors are highlighted in a study by Gott, Seymour, Bellamy, Clark and Ahmedzai (2004) where older adults, when asked their views about home as a place for end of life, expressed concerns over the practical and moral issues of their families' delivering the direct care they might need. Older adults are living longer with chronic diseases which by the advanced stages, mean the older adults are dying with higher levels of both physical and psychological symptom burden (Janssen, Spruit, Wouters and Schols, 2008). In order to manage these issues, families may require the support of home care workers whose availability is influenced by geographic and economic factors. There is also the added dimension of home care workers being an un-regulated workforce whose skills and knowledge around end of life care, can be extremely varied (Devlin and McIlfatrick, 2010).

In New Zealand from 2003-2007 national figures for all deaths showed most deaths occur in hospitals (34%), 31% died in Residential Aged Care and only 22% of deaths occurred at home (Naylor, 2011). Looking more closely at the older age groups within this data, from 2005-2007 significantly more people aged over 80yrs died in Residential Aged Care (40% of those aged 85 and over) and significantly less people in this age range died at home or in a Hospice In-patient unit.

Residential Aged Care Facilities

As a consequence, increasing numbers of older adults are living and dying in Residential Aged Care facilities. In New Zealand the figure for those over 65 years dying in RAC is 34%, the highest percentage of all the world's developing countries (Broad et al., 2011). A functional ability survey of residents living in Residential Aged Care facilities across the Auckland region of New Zealand was conducted in 1988, 1993, 1998 and 2008. The unique Older Persons Ability Level census or "OPAL" study demonstrates other interesting trends over a twenty year period (Boyd et al., 2011). The median age of a resident has risen from 83 to 85 years. Dependency has significantly increased across the total Residential Aged Care population with the largest high dependency proportion increase in Rest Homes from 16% in 1988 to 35% in 2008. Length of stay across all Residential Aged Care facilities decreased and on average, 20% of people admitted to Residential Aged Care survive less than 3 months and 40% survive less than 12 months.

In summary, the characteristics of residents entering Residential Aged Care facilities are that they are older, have multiple co-morbidities and their survival rate is shorter (Wowchuk, McClement and Bond Jr., 2006). When the disease is from non-malignant causes such as dementia, circulatory or respiratory disease, their death is more likely to be preceded by episodes of troublesome symptoms both physical and psychological and these episodes are "more prolonged than those associated with conditions such as cancer" (Davies and Seymour, 2002) p 974. This also makes it difficult to diagnose the end of life or "terminal" phase (Seymour, Kumar, and Froggatt, 2010).

Palliative Care and Residential Aged Care Facilities

Palliative Care is an approach which aims to improve the quality of life for a person with a life-limiting disease and their family. It promotes the importance of assessing their needs not only physical but emotional, social, spiritual, and cultural and emphasizes living well until death, extending into bereavement for those left behind (World Health Organisation [WHO], 2002).

Models of Palliative Care historically, have had cancer as a reference point (Gott and Ingleton, 2011) but the Palliative approach is seen to have increasing relevance in the care of those with non-malignant diseases (Froggatt, 2001) many of whom are older adults, living in Residential Aged Care facilities. There is much in the literature supporting the provision of Palliative Care for these residents (Kristjanson, Walton and Toye, 2005; WHO, 2005; Wowchuk et al., 2006) however, the Palliative Care needs of older people residing in care homes are not always recognized (McInerney, Ford, Simpson and Willison, 2009).

Surveys show that bereaved family carers have high levels of dissatisfaction of end of life care provided by Residential Aged care staff (Hall, Kolliakau, Petikova, Froggatt and Higginson, 2011; Miller and Mor, 2002,) citing poor assessment and management of symptoms particularly pain and failure to involve and inform families/poor communication (Stillman, Strumpf, Capezuri, and Tuch,2005). Seymour et al., (2010) mention the lack of consistent support from GP services to Residential Aged Care facilities and a reluctance to refer to Specialist Palliative Care services or if it occurs it is re-active rather than pro-active. Wowchuk et al., (2007) show staff in Residential Aged Care facilities lack knowledge about the practices and principles of palliative care and this was likely to increase the chances of inappropriate admissions of actively dying residents to an acute hospital. Waldron, Hasson, Kernohan, Whittaker and McClauglin et al (2008) state “staff in long term care facilities have plenty of experience of death and dying caring for dying residents but may lack formal training in palliative and end of life care” p1078 which according to Brazil and Vohra (2005), is necessary in order to provide good quality care.

Palliative Care Educational needs of staff in Residential Aged Care facilities

Indeed staff themselves identified that their lack of knowledge, formal training and skills in the Palliative Approach was a barrier to delivering high quality care to their residents in a survey by Whittaker, Kernohan, Hasson, Howard and McClauglin (2006). A literature search found that several authors across the developed world have explored the Palliative Care educational needs of Residential Aged Care Staff:-UK –Sidell, Katz and Komaromy, (1997) and Katz, (2003); Ireland – McDonnell, McGuigan, McElhinney, Teggart and McClure, (2009); Canada - Brazil and Vohra, (2005); Northern Ireland - Whittaker et al., (2006);

Australia - McInerney et al., (2009); USA - Ersek, Karybill and Hansberry, (2000). Here are some of their findings:-

A seminal study by Sidell et al., (1997) used a multi-method approach to look at the management of death and dying in residential and nursing homes across three regions in the UK. Sidell et al., (2000) argues “The head of the home sets the standard of care but the delivery of care is dependent on the quality of the care staff.” p 199. A postal survey to 1,000 “heads’ of homes” showed only 34% of them were familiar with the Palliative Care philosophy, 15% of these through personal experience of dealing with someone with cancer so saw no relevance of the Palliative approach for those residents with non-malignant conditions. Staff training was extremely limited with some staff undergoing no professional updating since qualifying. The research showed that through a lack of awareness of the benefits of a Palliative approach coupled with a shortage of resources, the staff were not delivering high quality care to their residents. Sidell et al., (1997) concluded that when caring for dying residents, most homes were isolated, reluctant to seek advice and support from external Specialists. A similar survey showed similar results 12 years later (Curry, Middleton and Brown, 2009).

Ersek et al., (2000) found several major issues for Residential Aged Care staff in American Nursing Homes following focus group interviews of Licensed staff (Registered Nurses) and certified nursing assistants (HCAs). There was a common theme throughout the study of the strong attachment staff felt for their residents. Topics that staff felt most strongly about included symptom management particularly pain with regards doses of analgesia and the fear of hastening death and/or addiction. Participants’ cited stressful interactions with residents, families and other health care professionals as well as lack of role clarity relating to expectations. They also felt inadequate when dealing with the uncertainty about goals of care which caused anxiety for them and lead to unmet self-care needs.

In a Canadian study, Brazil and Vohra (2005) used a postal questionnaire to survey licensed Long term Care (LTC-formerly known as nursing homes) facility staff mostly comprising of healthcare aides and personal support workers. (Only a small proportion of care is delivered directly by registered nurses). Brazil and Vohra (2005) found that although staff had much experience in caring for death and dying residents, very little had received any formal

education or training in Palliative Care. In fact at the time there were no educational standards required by the state of Ontario for LTC health care aides and personal support workers.

Other challenges found were over-burdened care providers and inadequate staffing levels which made releasing staff for training very difficult. LTC facility managers also stated that limited institutional resources made for very little provision for staff education in their budgets. Staff found the delivery of end of life care to be very stressful as they received little guidance in the principles and practice of Palliative Care.

Whittaker et al., (2006), surveyed qualified nursing staff from 48 nursing homes in Northern Ireland and found them to be educationally unprepared to provide high level end of life care. There were deficiencies in the nurse's undergraduate training leading to substantial gaps in their knowledge of Palliative Care. Less than half had obtained formal training in the area of pain assessment/management and only a quarter had obtained training on non-malignant conditions. The survey showed Qualified Nurses had a lack of awareness of Palliative Care principles with most based on personal experience. It also highlighted the need for enhanced liaison between Nursing Home staff and their local Specialist Palliative Care services.

In Ireland McDonnell et al., (2009) surveyed registered nurses (RGNs) and health care assistants (HCAs) working in "care of older person units" (Nursing homes) using separate questionnaires. A lack of awareness of Palliative Care principles was evident and how/when to refer residents with non-malignant diseases to Specialist Palliative Care services. Staff felt that the level of available support was inadequate but were unaware of the support offered by their local Specialist Palliative Care services to both them and their residents/families. HCAs were "unsure of their communication role" p453 when discussing death and dying issues with residents and families and lacked confidence in their ability to address residents/ and families needs. Both RGNs and HCAs surveyed had received little or no Palliative Care education over the previous 2 years.

Finally, an Australian study by McInerney et al., (2009) found similar issues to the previous authors' findings but this study using focus groups, included feedback from ancillary or nonphysical care staff. Communication issues were highlighted between Ancillary staff and physical care staff (RNs and HCAs). Ancillary staff in Residential Aged Care facilities (nursing homes) often develop trusting and close relationships with residents and their

families but are not usually included in case discussions. They are reliant therefore on RNs and HCAs passing on information about resident's conditions and needs and this study highlighted poorly developed "processes of information transfer" p350 compounded by rigid and hierarchical organizational structures. McInerney et al., (2009) also acknowledged that Ancillary staff were rarely included in education programmes as they were mostly for physical care staff.

Whittaker et al., (2006) suggests therefore, there are opportunities for improvement in RAC facilities based on education and training in palliative care.

Palliative Care Education for Residential Aged Care facilities.

For some time there was a paucity of available palliative care education for Residential Aged Care facilities (Katz, 2003; Stillman et al., 2005). The first published initiative from the UK commenced in 1996 and involved 55 UK Residential Aged care facilities, in a 2 year pilot project with the aim of addressing the Palliative Care needs of residents in Nursing Homes. It was jointly funded by Macmillan Cancer Relief. The educational component comprised of 12 days for RNs, 7 days for Healthcare assistants (HCAs) and 1 day for ancillary staff (Froggatt, 2000a).

A "comprehensive curriculum" was developed and delivered to licensed care staff (RNs) and certified nursing assistants (HCAs) in 44 Nursing homes in the USA entitled PERT- Palliative Care Educational Resource Team Program (Ersek and Wilson, 2003). The aim of the programme was to increase the knowledge, skills and confidence of RNs and HCAs regarding end of life care. It comprised of 4 day long, monthly classes. Separate classes for RNs and HCAs were held for symptom management but most were joint sessions to promote collaboration.

In 2009, a team from Northern Ireland (Curry et al., 2009) incorporated the Macmillan-validated programme of facilitated learning for care homes staff the "Foundations of Palliative Care" as a framework (Katz, Komaromy and Sidell, 2004) into a practice development model. Two nursing homes participated in a 10 month study of 2 x RNs 4 x HCAs offering 15 fortnightly, four hour sessions.

The content of all these education programmes covered topics such as the principles of palliative care, pain and symptom management, communication and bereavement care.

Evaluation

A vital component of any education initiative is evaluation, a means of measuring the effectiveness and worth of the programme not only to the educators themselves but to the stakeholders. The term evaluation is used across a variety of settings including business, academia and health and the literature is not short on definitions ranging from the simple to the complex. Patton (1986) defines evaluation explicitly as “the systematic collection of information about the activities, characteristics and outcomes of programs for use by specific people to reduce uncertainties improve effectiveness and make decisions with regard to what those programmes are doing and effecting” p126. Wilkes and Bligh (1999) offer a definition for educational evaluation and suggest that it is “the systematic appraisal of quality of teaching and learning” p1269. The dictionary definition states that learning is the act, process or experience of gaining knowledge or skill. Worrall (2007) defines evaluation in healthcare education as “a systematic process by which the worth or value of something, in this case teaching and learning, is judged” p 558. From these definitions common themes evolve-process, systematic, value, improvement.

However, Bailey and Littlechild (2001) argue that choosing the right definition and having clarity of meaning is important prior to embarking on an evaluation process as this will help shape the strategy or framework to be applied to a programme.

Evaluation is used to inform the facilitator of not only how the learning is during the teaching (formative) but also informs the facilitator on the outcome or effects of the education after it has been carried out (summative).

“When a cook tastes the soup it is formative evaluation, when the dinner guest tastes the soup, it is summative evaluation.” (Harvey, 1998 p 7).

Approaches to evaluation require answers to key questions and one of the most crucial is ‘What is the focus of the evaluation?’ This needs to include, according to Worrall (2007) five basic components:

1. Audience- this would not just include those participating in the education sessions or programme but also those who would be using, benefiting from, or have requested the evaluation data.
2. Purpose - this needs to be clear and audience focussed.
3. Questions - these need to relate to the purpose and should be measurable and specific.
4. Scope - how much is to be evaluated and will depend on the purpose and available resources.
5. Resources - obviously dependent on time, financial constraints, staff availability and skill.

The evaluation process itself needs to be reliable, objective, feasible and valid and these terms require some definition. Course evaluators are very often the same people who have delivered the education and therefore may find it difficult to be objective in the evaluation process. It can be beneficial to therefore utilise a collaborative approach by using external evaluators (Bailey and Littlechild, 2001).

Reliability and validity of the information gained through evaluation can be influenced by organisational bias, role conflicts and response rates. Piloting evaluation tools can help as can re-testing participants knowledge and skills at a later date using rating scales. (Campbell, 2007). There is a general consensus in the literature that the data gathered should be used as intended and that the evaluation tools should measure what they were intended to measure (Billings and Halstead, 2005; Worrall, 2007). Feasibility is concerned with practical issues such as “Can this work? / Is it possible with the available resources and within the scope of the evaluation?”

The use of a model or framework can help guide this process. This will be discussed in more detail in the Methodology section under Study Design.

The impact of health care education interventions needs also to be determined on care outcomes (Wowchuk et al., 2007) however few empirical studies actually show how education affects practice (Griscti and Jacona, 2005) and there is lack of standardized measures for attitudinal and behavioral change (Atree, 2006).

Evaluating Palliative Care education delivered in Residential Aged Care facilities.

With the emergence of Palliative Care Education programmes specifically targeted at Residential Aged Care staff, there followed several studies evaluating the effectiveness of the education. Most cited in all the literature is Froggatt (2000a) who evaluated the Macmillan funded education initiative conducted in the UK. The aim of the study was to identify the nature of the impact of the education programme had on individual course members, participating nursing homes and the care delivered to residents and their relatives in the nursing homes. The method used by Froggatt (2000a) involved case studies from 4 of the 54 participating nursing homes using participant observation and taped interviews. Froggatt (2000a) also utilized postal surveys of 54 participating and 119 non-participating nursing homes and finally, interviewed key people involved in the programmes development and delivery. Findings from this multi-method approach were: improved pain control for residents; improved communication with residents; and a greater awareness of the needs of relatives. Closer links with other professionals were also established, particularly with local Specialist Palliative Care Services. However, Froggatt (2000b) (Executive summary-from the abridged report) found “the primary determinant of the impact of the educational courses on patient care, was the organisational culture which prevailed within individual nursing homes.” Therefore recommendations given by Froggatt in the executive summary (Froggatt 2000b) were to include the creation of two new roles. Assign a Specialist Palliative Care practitioner to a small geographical location to work collaboratively with nursing home management re: practice development and educational needs of all levels of care staff. This role would also work alongside staff in their own environment to implement the new knowledge gained through the education. The other role would be a facilitator in Palliative Care for older people/Gerontology Nurse Specialist again assigned to a small geographical location to work collaboratively with the different organizations and professionals involved.

The evaluation methods used in this well designed study were of high quality. Evaluation data was collected from a variety of sources but the care outcomes were from the Staffs' perspective, not sought directly from the residents and families themselves.

Stillman et al., (2005) in an American study evaluated a programme which consisted of staff training focusing on 3 areas; advance care planning, symptom management and psycho-social support. The program incorporated on-going consultation with an expert nurse and corporate support and involved six care homes, two were a control. The study aim was to determine whether the presence of a comprehensive Palliative Care education program in nursing homes would affect the knowledge and attitudes of the staff. The initial 2 day course was delivered by expert nurses and then a designated palliative care co-coordinator from the nursing home (RN or Social worker) took responsibility for the delivery of the on-going training programme. A questionnaire comprising of 9 items measuring knowledge and attitudes around Palliative Care issues was completed by all staff immediately following the completion of the education programme and repeated one year later. The study findings suggest that a Palliative Care Program increases knowledge about care of the dying and increases staff awareness of Palliative Care issues and that this increases over time. Stillman et al., (2005) recommend that this is achieved by using an interdisciplinary approach to training and consultation. However, their findings concur with Froggatt (2000a) in that to affect a change in culture for care home staff with regards attitudes and knowledge of Palliative Care issues, Stillman et al., (2005) suggest a broader initiative aimed at care delivery processes, was necessary.

This study was more rigorous in that it incorporated a control group comprising of 2 care homes who did not receive the education and comparisons were made. It also re-surveyed participants after one year to observe whether the changes had been sustained over time.

Curry et al., (2009) chose a Practice Development Approach in a study of two nursing homes in Northern Ireland. Two RNs and four HCAs from each facility were nominated by the facility manager. The study aimed to explore and address the Palliative Care education needs of staff working in nursing homes. Using the Foundations of Palliative Care produced by MacMillan Cancer relief (Katz et al., 2004) as its framework, fifteen, four hour sessions were co-facilitated by Specialist Palliative Care nurses over a ten month period. The facilitators

utilized collaborative group work and reflective learning throughout the process to enhance understanding and appreciation of others' roles. Values clarification was used to explore beliefs and develop a shared vision for Palliative Care provision in the nursing home setting. Curry et al., (2009) found at the completion of their study, by using a Practice Development Approach, the outcomes achieved demonstrated a link between the education delivered and practice through action plans identified by the individual facility. This resulted in a range of Palliative Care initiatives instigated by each of the participating nursing homes such as life review, development of a Palliative Care guideline and mission statement and clinical supervision for staff.

This study was much smaller in comparison to Froggatt (2000b) and Stillman et al., (2005) but it took a slightly different approach. Not only did Curry et al., (2009) evaluate the impact of the education but the participating nursing homes were encouraged to develop an action plan of a Palliative Care initiative relevant to their organizational need. These initiatives were instigated thereby demonstrating something tangible, a legacy so to speak of their learning experience. Participants also completed a baseline questionnaire before commencement of the project which the aforementioned studies do not appear to have undertaken.

I could find no published articles on Palliative Care education delivered to all staff in Residential Aged Care facilities in New Zealand. Thus there is a gap in the literature and a need to understand what Palliative Care education for New Zealand Residential Aged Care facilities is occurring and how effective they are.

Palliative Care Link Nurses

One of the recommendations made by Froggatt (2001), following her seminal study was to integrate Palliative Care with nursing home practices. She argued that existing knowledge of care home staff needed to be recognized and that expertise from this care setting and Specialist Palliative Care teams should be shared by working collaboratively in order to understand and meet the needs of the older adult. One way to achieve this is by the development of a Palliative Care Link Nurse role, Registered Nurses with a passion for Palliative Care facilitating two-way communication between the Residential Care home and

their local Specialist Palliative Care provider. Hasson, Kernohan, Waldron, Whittaker and McLaughlin (2008) suggest qualities of the Link Nurse must include background knowledge in Palliative Care, ability to support, educate and develop others and be in a position to implement change. Positive impact of the Link Nurse role was highlighted by Heals (2006) in the UK with evidence of more effective symptom assessment and management, improved communication skills and a more proactive approach, care planning as opposed to crisis management for residents in Residential Aged Care facilities with a designated Palliative Care Link Nurse. Phillips, Davidson, Ollerton, Jackson and Kristjanson (2007) found that establishing a Link Nurse role in Australian care homes empowered aged care nurses and a combination of new knowledge and greater confidence and led to the prevention of unnecessary hospital admissions for end of life care. However, the role does not come without its difficulties and these include releasing Link Nurses to attend meetings/education sessions, information not being disseminated to care home staff by the Link Nurse and lack of managerial support making changes in attitudes and practice very difficult (Hasson et al., 2008; McIlpatrick, Mawhinney and Gilmour 2010; Waldron et al., 2008.)

In introducing Link Nurses to the New Zealand setting similar issues were encountered (personal experience).

Organisational Culture

The literature frequently alludes to the organisational culture of Residential Aged Care facilities and its influence on changes in attitude and practice in relation to promoting a Palliative Care approach for its residents. (Froggatt 2000a; Phillips, Davidson, Jackson and Kristjanson 2008; Wowchuck et al., 2007). Nolan, Featherston and Nolan (2003) suggest that the introduction of a Palliative Care philosophy in Residential Aged Care facilities depends heavily on the integrity of the staff in those facilities. They go on to argue that this integrity needs to be nurtured and supported by institutional structures and cultures and that investment in education is crucial. In my experience delivering education and supporting the Palliative Care Link Nurses in Residential Aged Care facilities, much depends on the capacity of the facility managers to provide on-going support for their staff with regards professional development and their own understanding of the Palliative Care approach. When the facility

manager and the Link Nurse are on “the same page” with regards their philosophy of care and have a deep understanding of the needs of their residents and staff, it positively influences their organizational culture.

Indeed, Froggatt (2000a) found that following delivery of Palliative Care education “Without having a manger who is committed to developing practice, individual course members would be isolated in their attempts to change care” p 145.

Culture and Ethnicity

“Culture influences communication patterns, decision making styles, responses to symptoms, treatment choices and emotional expression at end of life” p 510 (Bosma, Aplan, Kazanjian, 2010). This quote captures beautifully the complexities of delivering Palliative Care in a multi-cultural society.

It is applicable not only to those receiving Palliative Care but to those who deliver it and those professionals like myself who promote and advocate its approach. The Palliative Care approach is a Western concept, the patient central and autonomous, encouraged to make informed decisions about treatments and actively involved in advance care planning. Underpinning this philosophy are open and honest discussions had by health care professionals (usually doctors and nurses) and the patient, about diagnosis, prognosis and possible outcomes (Chater and Tsai, 2008).

However, this Western ethical notion of autonomy conflicts with the inherent belief systems of some cultures with family duties and obligations taking precedence over patient autonomy (Cooper and Glaetzer, 2004). The main reason for non disclosure, not telling the truth is often nonmaleficence, not wanting to do harm (Chan, 2011). Bowman, Singer and Richard (2004) suggest therefore that health professionals need to be aware of patient’s values and beliefs and should ask patients whom should be given the information. This way, “true autonomy does not preclude the right to know but rather the right to choose not to know” p 411 (Bowman et al., 2004).

The growing diversity of ethnicities amongst staff in Residential Aged Care facilities brings another dimension when trying to encourage a Palliative Care approach is delivered to all residents and their families/whānau. A staff member from a culture where open discussions around death and dying are thought to be inappropriate because they might cause harm will be very reluctant to initiate conversations with their resident around advance care planning for example. Compounding this is also the fact that English may be a second language for these staff leading to potential communication difficulties (Ersek, Kraybill and Hansberry, 1999).

Think of the New Zealand/European resident, an older adult who may also have auditory and visual impairment but whose expectations are to be an autonomous decision maker being cared for by an Registered Nurse from a Chinese culture with English as a second language, who believes that she will do harm to the well-being of her resident if she discusses directly with him/her their diagnosis/prognosis.

In her article “Palliative Care and Nursing Homes: where next?” Froggatt (2001) argues that four assumptions have been made in the promotion of Palliative Care approach in Residential Aged Care facilities. The first is that the transfer of knowledge from a Specialist Palliative Care setting to Residential Aged Care is unproblematic. She speaks of a different culture in care between Hospices and Nursing homes where there is less distinction from life to death in a nursing home as opposed to “clearer demarcation” that occurs for patients who die in Hospices. The second assumption involves the model of care. Specialist Palliative Care has predominantly cared for people with cancer and that model of care does not translate well to those with a non-malignant illness such as organ failure, dementia or degenerative neurological disorders. The third assumption is that staff in Residential Aged Care facilities do not know how to care for residents who are dying. There is also a lack of recognition of their specialist skills in dealing with the older adult living with chronic conditions. The final assumption is that education alone is sufficient to bring about changes in attitude and practice.

There is a need for the clinical teams supporting the Residential Aged care facilities to work in collaboration, these include GPs, and the Specialists and Allied Health teams involved in the care of the residents.

Summary

The literature review has shown that Residential Aged Care is a common place for older people to die, there have been successful programmes overseas to improve the care of older people with Palliative Care needs living and dying in this care setting but little information is available in New Zealand.

The Research Study Aim

Understanding the lack of information about Palliative Care education in New Zealand for Residential Aged Care staff, this thesis reports the evaluation of an education programme.

The aim is: to establish the impact of a Palliative Care education programme on views of staff in Residential Aged Care in New Zealand.

2. METHODOLOGY

This thesis reports the evaluation of an educational programme for Residential Aged Care. First I outline the programme and its delivery and then the methods by which the programme was evaluated.

Background: Development of the Palliative Care Education Programme

In February 2010 working collaboratively, the four Hospices of the Waitemata District Health Board (WDHB), Hospice North Shore, Hospice Hibiscus, Hospice West Auckland and Warkworth/Wellsford Hospice successfully obtained funding through a tender process to design, deliver and evaluate, meaningful evidence-based Palliative Care education to all staff working in Residential Aged Care (RAC) facilities, contracted to the WDHB. The general aim as stated in the WDHB Service Specifications “is to improve the outcomes for people and their families/ whānau living with life limiting illness which is expected to lead to death.” The WDHB wanted the education to be delivered on site, attendance free of charge and the Hospices were to report quarterly statistics including outcome measures to the Ministry of Health.

The WDHB Palliative Care Education programme team of four Hospice Educators and an administrator conducted a learning needs analysis (LNA) of all staff from 1/3rd of the RAC facilities across the WDHB. Results showed the predominant role in RAC facilities was Health Care Assistant (60%) and 40% of participants stated English was their second language. There was a wide range of ethnicities represented. Here is the breakdown:

Table 1 - Ethnicity of staff working in residential aged care

Chinese	12
Fijian	7
Indian	28
Maori	27
NZ	153

Tongan	16
Samoan	15
Philippine	58
Other	64

The Learning Needs Analysis gave a selection of topics related to Palliative Care and asked staff their preferences in order of priority, staff were also offered an opportunity to highlight areas of concern, when caring for residents with Palliative Care needs and their family/whānau. The education programme incorporated the favoured topics from the Learning Needs Analysis as well as local guidelines produced by the Waitemata District Health Board (WDHB) Residential Aged Care Integration (RACIP) working group, to promote consistency in practice across the district (www.waitematadhb.govt.nz). The RACIP working group is a quality improvement initiative and comprises of WDHB Residential Aged Care managers, Gerontology Nurse Specialists and Hospice representation.

The aim of the Palliative Care Education Programme was to raise awareness and increase confidence of palliative care issues for Residential Aged Care staff. We envisaged this would be achieved through building on their existing knowledge and skills.

The content of the programme was decided using the information from the Learning Needs Analysis, evidence based practice, education theory and the experience of the Hospice Educators who had been delivering education in similar care settings. Penz and Bassendowski (2006) suggest that evidence based practice incorporated into clinical settings can improve patient outcomes and this was the general aim of the education programme. RAC facility managers had stated one hour was the maximum time they could free staff to attend so the education programme team divided this time into 30 minutes theory using a power point presentation with accompanying handouts for participants and 30 minutes discussing case studies relevant to the session topic, linking the theory to practice. Adult learning theory suggests forming links helps with understanding and promotes a deepening of the learning (Forrest 2004). The education team wished to build on the existing knowledge and skills of participants and valued what each person brought to the session. Discussing Palliative Care

issues often evokes emotional responses and can trigger personal experiences of loss for some participants. Relf and Heath (2007) argue “such experiences also present powerful learning opportunities and participants often develop a better understanding of both self and others” page 161.

The Hospice Educators were therefore keen to ensure that the learning was conducted in a safe environment. Ground rules were agreed upon with participants at each RAC facility and revisited each time a session was held. These can be found in Appendix 1.

The case studies involved small group discussions and allowed the participants to work together in teams of mixed roles and skills. There were representatives from a wide range of diverse cultures at each session, many with English as their second language. The interaction was often very animated during the case studies, participants feeling more comfortable to share their experiences than when discussing issues in the larger group. To keep the education meaningful, the case studies were chosen from real life clinical cases experienced by the Hospice Educators whilst working in a RAC setting. Here are two examples of case studies along with the Hospice Educators facilitator’s notes.

Session 1 - Nausea and Vomiting; Nutrition and Hydration. Case Study 1:

A 68 year old female resident is vomiting; she has a chest infection and is on oral antibiotics. She has oral thrush, is losing weight and feeling nauseous, worse prior to meals. Her room is next door to the kitchen. She is very anxious particularly when her family leave. What can you do in your role?

Facilitator Notes: Stress the importance of an accurate assessment. What is causing the vomiting? Avoid chewy foods; rather choose foods easy to chew, swallow and a light diet. Not

sure of this lady's cultural background, she may have a particular diet that she requires, could family maybe bring in some home cooking if facility allows this (storage OSH issues etc.)?

Move her to a room away from the kitchen if possible.

Treat oral thrush. Mouth care with ice blocks to suck and or lip balm. Help anxiety with relaxation or diversional therapies. Nebulised saline and or physiotherapist treatment. Is she swallowing phlegm and is this causing the vomiting?

Antibiotics; are they causing the nausea? May need to change them. Report to the RN. Document. Check fluid balance and bowel chart. On-going evaluation.

Session 2 - Pain Assessment and Management. Case Study 2:

Mr. Salu is an 83 year old Samoan man who cannot speak English. His family interpret for him. He has an end-stage malignancy. He is no longer able to communicate verbally but is showing facial grimacing and moaning whilst undergoing personal cares and turning. His large extended family stay with him around the clock. Before he became very unwell, Mr. Salu stated "I want to go home to Samoa to die." What are your observations? What can you do in your role? Who would you need to involve?

Facilitator Notes: Observations: Mr. Salu wishes to go home to die but is obviously not going to make it to Samoa. He cannot speak English. All information is going via the family; is the information accurately translated? And that's both ways. Refer back to perception slide (19), and the total pain slide (20), the Te Whare Tapa Wha model and WHO definition of palliative care.

What would you do in your role? Set up a family meeting. Liaise with cultural health representatives.

Who would you need to involve? Arrange a Family meeting. Involve the Doctor; regarding pain. Include a support person for the family (and this might be a spiritual support person). Discuss the feasibility of Mr. Salu travelling to Samoa? Need to look at 'burden versus

benefit'. If this is not possible, then bring Samoa to him! Music, items from home, offer family to help with hands-on care if they would like to. Possible pharmacological management, perhaps with a Syringe driver, clonazepam drops (rectal medication not appropriate for this culture). Tell group what happened in reality for this man (name was changed to preserve anonymity). His extended family came to New Zealand to care for Mr. Salu and this solved some of his spiritual distress since he could not travel to Samoa. His family stated that he was "Living in love".

We soon realised that not all staff would be able to attend each session therefore we had to have some core components within each session which reinforced a consistent message. These included the definition of Palliative Care and how it aligns to the Māori Model of health-Te Whare Tapa Wha (Durie, 2004), the importance of the Holistic approach to care involving cultural, spiritual and psychosocial considerations and the role of the family/whānau. We sought advice from a member of the WDHB Māori Advisory Group and a member of the WDHB Asian family support services to ensure that our content was culturally appropriate. I also spoke to both groups during the process of seeking ethics approval for the research study and had supportive letters (Appendix 2).We emphasised the importance of an accurate assessment as it is a vital component in palliative care. This approach also reflects the aim of the education programme which was “raising awareness and building confidence” rather than expecting staff to come up with solutions to complex problems. (We had no expectations that an HCA would be able to solve a complex problem, rather they had the skills to assess accurately and report their observations appropriately.)

The topics delivered over 6 consecutive weeks are shown in Table 2.

Table 2 - Content of WDHB Palliative Care Education programme for all Residential Aged Care staff

Session 1	Nausea and Vomiting; Nutrition and Hydration
Session 2	Assessment and Management of Pain in Palliative Care
Session 3	Communication: Dementia/Delirium, Depression, Advance Care Planning

Session 4	Breathlessness, Fatigue and Constipation
Session 5	End of Life Care; Recognising dying
Session 6	Grief, Loss and Bereavement; Self Care

The delivery of the WDHB Palliative Care Education Programme commenced in June 2010 and was completed in June 2012. I sought ethical approval February 2011 to conduct focus group interviews on the remaining 17 of the 25 facilities on the North Shore.

The table shows details of the 25 facilities and those highlighted, participated in the research study.

Table 3 - Schedule of delivery of the WDHB Palliative Care Education Programme - June 2010 - July 2012

Facility	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6
PH	08/01/2012	15/02/2012	29/02/2012	07/03/2012	14/03/2012	21/03/2012
RH	20/09/2010	27/09/2010	04/10/2010	11/10/2010	18/10/2010	28/10/2010
PH	04/08/2010	11/08/2010	18/08/2010	25/08/2010	01/09/2010	08/09/2010
RH	14/09/2011	21/09/2011	28/09/2011	05/10/2011	12/10/2011	26/10/2011
FG2-PH	01/06/2011	08/06/2011	15/06/2011	22/06/2011	29/06/2011	06/07/2011
SDU	07/02/2012	14/02/2012	21/02/2012	28/02/2012	06/03/2012	13/03/2012
RH	29/03/2012	05/04/2012	12/04/2012	19/04/2012	26/04/2012	03/05/2011
PH	29/06/2010	06/07/2010	13/07/2010	27/07/2010	03/08/2010	17/08/2010
PH	24/05/2011	31/05/2011	07/06/2011	21/06/2011	28/06/2011	12/07/2011

Facility	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6
PH	05/08/2010	12/08/2010	19/08/2010	02/09/2010	15/09/2010	23/09/2010
PH	21/10/2010	27/10/2010	03/11/2010	17/11/2010	24/11/2010	01/02/2010
RH	08/05/2012	15/05/2012	22/05/2012	29/05/2012	05/06/2012	12/06/2012
FG3-RH	13/07/2011	21/07/2011	03/08/2011	10/08/2011	17/08/2011	31/08/2011
FG4-SDU	09/06/2011	16/06/2011	23/06/2011	30/06/2011	07/07/2011	14/07/2011
FG1-PH	21/03/2011	28/03/2011	11/04/2011	18/04/2011	02/05/2011	09/05/2011
RH	01/11/2010	08/11/2010	15/11/2010	22/11/2010	29/11/2010	06/12/2010
PH	28/03/2012	04/04/2012	11/04/2012	18/04/2012	02/05/2012	09/05/2012
PH	29/03/2011	5/04/2011	19/04/2011	3/5/2011	10/05/2011	17/05/2011
RH	27/03/2012	03/04/2012	10/04/2012	17/04/2012	24/04/2012	01/05/2012
PH	17/06/2010	24/06/2010	01/07/2010	08/07/2010	15/07/2010	29/07/2010
RH	N/A	N/A	N/A	N/A	N/A	N/A
RH	13/09/2011	27/09/2011	04/10/2011	25/10/2011	01/11/2011	15/11/2011
PH	14/04/2011	21/04/2011	05/05/2011	12/05/2011	19/05/2011	02/06/2011
RH	10/05/2012	17/05/2012	24/05/2012	31/05/2012	07/06/2012	14/06/2012
FG5-RH	26/07/2011	02/08/2011	16/08/2011	23/08/2011	30/08/2011	06/09/2011

Study Design

The study design chosen is a qualitative research methodology because its principal purpose is to understand the significance of human and social understanding.

The four Hospice Educators, who developed and delivered the Waitemata District Health Board (WDHB) Palliative Care Education programme, used Kilpatrick's Evaluation model (Kilpatrick, 2005) as the framework to evaluate the programme which involves 4 stages; Level One - Reaction, Level Two - Knowledge improvement, Level Three - Change in behaviour and Level Four - the impact of the education.

Attree (2006) suggests that most studies do not address educational outcomes beyond Level 1 and 2. Quantitative evaluation tools are used currently by the Hospice Educators to collect formative evaluation data (Levels 1 and 2) but searching for evidence of Levels 3 and 4 of Kilpatrick's model is required. By conducting focus-group interviews, I hope to measurably link the process of education to the Education Programme outcomes. These are to raise awareness and increase confidence of Palliative Care issues for residential Aged Care staff through building on their existing skills and knowledge. The general aim as stated in the WDHB Service Specifications "is to improve the outcomes for people and their families/whānau living with life limiting illness which is expected to lead to death."

The aim of the research study therefore is to "Explore the impact of a Palliative Care Education Programme.

Demonstrating measurable outcomes to the WDHB will secure on-going funding from the WDHB. The whole programme has been funded by them and part of the WDHB contract with the 4 Hospices, is to be able to demonstrate the programme's effectiveness. If evidence can be provided, the more likely it is that the WDHB will continue on-going district wide support for this programme. Ultimately this would enable good palliative care to be delivered across all RAC facilities and improve relationships, sharing of knowledge both ways, and promote collaborative working between Specialist and Generalist Palliative Care providers. This thesis forms part of an overall evaluation and I am reporting on the aims as stated clearly. This may lead to alterations in programme content, mode of delivery, and or reveal other issues that influence the linking of theory to practice and what needs to happen to support the education.

This would also have implications nationally as it would inform other Hospice Educators so they might work more effectively, prevent re-inventing the wheel. A robust evaluation process will enable the four WDHB Hospice Educators to look at the potential transferability of this Palliative Care Education Programme to other care settings.

Participants and recruitment

Participants were selected purposively from each of the 17 Residential Aged Care (RAC) facilities across the North Shore region in the WDHB to ensure a cross section of facilities were represented. Kidd and Parshall (2000), believe that “for purposes of peer reviewed social and health research, confidence in focus group findings almost always can be enhanced by conducting multiple groups (ideally from multiple sites),” p 305.

Following ethics approval, a letter was sent to five RAC facility managers (Appendix 3). These included two Private Hospitals, two Rest Homes and one Secure Dementia Unit. The RAC facility managers were asked to approach staff who had participated in at least 4 to 6 of the WDHB Palliative Care Education programme sessions and invite a maximum of eight of them to participate in a one hour focus group, four to six weeks post programme delivery. Due to the delay in ethics approval being obtained, this time frame was longer for some facilities.

The RAC facility managers were given information sheets for themselves and participants (Appendix 4 and 5) along with consent forms (Appendix 6 and 7) and interview guides (see Appendix 8). I discussed the research study with the RAC facility managers and explained how the focus groups would hopefully give evidence of the worth of their staff attending the WDHB Palliative Care Education Programme and how it might benefit both staff and their residents with Palliative Care needs.

When the RAC facility managers informed me that they had interested staff willing to volunteer to participate in the focus groups, I set up a meeting on site and went through the documentation, answering any questions. I showed them the signed confidentiality agreements of the researcher, interview facilitator and co-facilitator (Appendices 9-12). I then collected the signed consent forms from the RAC manager and participants.

Focus groups

The participants actively engaged in group work activities during the education sessions facilitated by the Hospice Educators so I felt that this study method would be acceptable. Focus groups capture individuals' personal experiences and beliefs about a defined area of interest, in this case of participating in a Palliative Care Education Programme (Sim, 1998). They have been found to be particularly useful in health research and an effective technique for exploring the attitudes and needs of staff (Kitzinger, 1995). Seymour, Bellamy, Gott, Ahmedzai and Clark (2002) suggest that "When members are already known to each other focus groups provide two purposes, providing a familiar and supportive environment for the participants and of introducing the researcher to the cultural values of the organisation." p 519.

An independent practitioner with experience in similar work facilitated the focus groups using an interview guide to prompt discussion about the programme (see appendix 13). The facilitator identifies with European ethnicity, she is an RN, her role is Nurse Leader for a Hospice and she has a Masters in Ethics. A second member of the Waitemata District Health Board (WDHB) Palliative Care Education team but who did not facilitate the education sessions to the focus group participants was present for the purpose of co-facilitation. This person was not involved in data analysis. Focus groups were held on site in a private room, participants were made comfortable and the focus groups lasted one hour.

The independent practitioner asked participants to complete a demographic form (Appendix 14). In total, 26 participants took part in the focus groups (see Table 4).

Table 4 - Statistics from Demographic Form – Focus Groups – WDHB Palliative Care Education Programme 2012

Question	Results									
Age Group:	20-29 2	30-39 2	40-49 8	50-59 6	60-69 6	Not reported 2				
Ethnicity:	NZ/Pakeha 5		European 2		Maori 5		Pacific Island 1	Asian 12	Other 1	
Gender:	Male = 1				Female = 25					
Job Title & Grade:	Cleaner 1	HCA 16	HCA/Cook 1	Manager 1	HCA/Cleaner 1	Office Admin 1	RN 4	RN & Manager 1		
Employer:	PH FG2 7		RH FG3 3		DCU FG4 4		PH FG1 7	RH FG5 5		
Part time/Full time:	Part-time = 6			Full-time = 19			Not reported = 1			
Professional Qualifications:	ACZ Course 1		Bachelor of Nursing 1		Dip in General Nursing & Midwifery 1		Diversional Therapist 1		EN 1	MA/Dip 1
	Masters in Mechanical Engineering 1		O/S Bachelor Degree (BSN) 1		O/S Degree Grad (BSc) 1		RN 4		None 2	Not reported 11
Length of Time at this Residential Aged Care:	6 months 1		8 months 1		9 months 1		10 months 1		1 year 2	1yr 3mths 1
	2 years 1		3 years 2		4 years 3		5 years 1		6 years 1	8 years 3
	10 years 1		12 years 2		19 years 2		27 years 2		28 years 1	
Length of time in similar jobs:	9 months 1		2 years 2		4 years 1		6 years 1		7 years 3	9 years 1
	14 years 1			15 years 1			None 6		Not reported 9	
Extent of Palliative Care Training:	In-Service 5		WDHB Palliative Care Education Programme only 17		Assisting in several deaths 1			Not reported 3		

The interview guide (Appendix 8) comprised of the following open questions which were used to guide the discussion:

1. How has the education affected you personally?

2. How has the education affected your role at the RAC facility?
3. How has the education impacted on how you care for the residents with Palliative Care needs in your facility?

This method will maximise comparability of responses across all the focus groups and will minimise the effects of the interviewer.

During the focus groups, the facilitator noted that participants were emotional at times when reflecting on the impact of the education, particularly when recalling personal losses through death in the family and with residents they had cared for in their RAC facility. Hudson (2003) warns us that given the emotive issues surrounding Palliative Care it is very important that participants are given additional support and attention during the interview. The same ground rules used in the WDHB Palliative Care Education Programme sessions (Appendix 1) were utilised in the focus group interviews, these were on the Participant information sheet (Appendix 5). Staff were offered time following the interview to discuss any concerns or issues that had arisen during the interview. One participant was given written information about how to access grief counselling.

Method of Analysis

Focus groups were audio taped and transcribed verbatim. I used the General Inductive Approach as described by Thomas (2006). Focus group interviews generate a significant amount of raw data so I needed a framework to ensure a systemised approach to the data analysis. Focus groups permit participants to discuss their views by social interaction and the general inductive approach is less constraining than other structured methodologies (Buetow, 2007).

The aim of this study is to explore the impact of a Palliative Care Education programme. To search for evidence of application of learning to the practice setting and improved care outcomes for residents with palliative care needs. These aims guided the analysis and by using the general inductive approach, enabled transparent and defensible links to be established between them and the summary findings (Thomas, 2006). The interview questions

are open thereby allowing me to develop themes from the text data. Each participant's comments could only be identified by their role, ethnicity and the type of facility e.g. PH-Private Hospital, RH-Rest Home, SDU-Secure Dementia Unit.

I read the transcripts from the five focus groups several times to familiarise myself with the content and immerse myself in the data. Using the research study aims to help me identify topics to investigate, I then re-read the transcripts. I started to carefully identify sentences and phrases that I felt were meaningful to establish the range and depth of participant's views about the impact the education had had on them personally, in their role at the Residential Aged Care facility and the care they gave to residents with Palliative Care needs. To these specific text segments I then assigned a code and developed themes using a digital highlighter. I performed this task across all transcripts and continued until I was satisfied that no new themes emerged. I then used cut and paste process for the data pertaining to one theme across all transcripts and repeated this for all the other assigned categories. I did this so I could read all the comments from one assigned category at a time to look for any commonalities and or differences. I also noted how many times a particular category occurred across all transcripts.

Using A3 paper, I made cut outs of all the theme labels, there were 18 in total and I arranged the individual theme labels across the sheet. Using Blu-Tac®, I grouped together several categories moving and changing the groupings several times. The purpose of a General Inductive Approach is to identify core meanings, those most relevant to addressing the study aims, (Thomas 2006). What I was attempting to do was summarise the 18 categories into more succinct terms or main themes which reflected the views and attitudes of the participants of the impact of the WDHB Palliative Care education. The themes were constructed into a tree and revised.

I was mindful that the themes should come from the data rather than be superimposed according to preconceived notions. I aimed to be guided by the participants, listen to what they are telling me. Patton (1990) argues that the quality of the research depends heavily on the qualities of the researcher as a human being, the researcher being the instrument of qualitative inquiry.

I was also aware of the research objectives which were to search for evidence of the impact of the WDHB Palliative Care Education. There were some comments made by participants about the care they delivered to residents or situations that they had come across but I needed to always ensure I could demonstrate that it was linked to the WDHB Palliative Care Education programme delivery.

Using criteria for trustworthiness of qualitative research

To establish credibility of the findings, following analysis of the raw data, I asked a colleague, another Hospice Educator who had been delivering the education in a different part of the WDHB district, to conduct independent parallel coding (Thomas 2006). I gave her the five transcripts and the research objectives and without seeing my categories, she created a second set. We then sat together and compared the category labels she and I had formulated. During this discussion we looked at the categories that we had devised, the terms we had both given to describe the categories. In some cases we merged categories but pre-dominantly it was very noticeable that there was considerable overlap.

This agreement between the two coders is considered good. The aim of this exercise was to assess the trustworthiness of my findings and Guba and Lincoln (1989) suggest that this process helps qualitative researchers demonstrate the credibility of their research (see table 5).

Table 5 - Theme coding trees / coding consistency checks

Attitude and behaviour change

Researcher codings	Coding consistency checks
Raised awareness of Palliative Care	<i>Raised awareness. Understand the Holistic connection.</i>
Increased confidence	<i>Reduced avoidance. Increased confidence. Increased professionalism.</i>
The needs of the family	<i>Family as well. Listening to family. Talking with the family. How important it is for family to be part of the process.</i>
Cultural Awareness	<i>Increased cultural awareness.</i>
Improved my way/changed my outlook/made me think	<i>Increased insight. Course has made me think about things. An eye opener.</i>
Increased job satisfaction	<i>More satisfaction from the job.</i>
Reduces personal stress	<i>Increased coping. Less fearful. Reducing stress.</i>

Existing Knowledge

Researcher codings	Coding consistency checks
Building on existing knowledge & skills	<i>Reinforces a lot of what we are already doing. I think we know more than we did.</i>
Validation/Affirmation	<i>Affirmed. Enhance some of your skills. Validated my instincts.</i>
Acknowledgement of the HCA role	<i>Acknowledge us Health Care Assistants</i>
Benefit of whole team learning together-coming from the same place	<i>Increased trust amongst staff</i>

New Knowledge

Researcher codings	Coding consistency checks
Increase knowledge/understanding	<i>Increase understanding. Increased knowledge of chronic conditions. Symptom relief.</i>
Resource to refer back to	<i>We've got tools & resources that we can refer to.</i>
Grief Loss & Bereavement	<i>Grieving. Personal Understanding.</i>
Advance Care Planning	<i>Increased planning.</i>
Dissemination of new knowledge to other/new staff	<i>Educate new staff</i>
Communication	<i>Better handover. Increased communication. Report things.</i>
Improved Assessment Skills	<i>Recognising dying quicker. Good observation skills. Better/regular assessment. Ask better questions.</i>

Another way is by conducting member checks where participants are offered the opportunity by the researcher, to check emerging findings that ensure they are satisfied with the interpretation placed on their comments (Clissett, 2008). Two of the focus groups were approached to participate in member checks which consisted of a 30 minute meeting at their work place. Attendance was voluntary and most of the original group members were able to attend. Using the A3 sheet with the arranged themes, I described to the participants, how I intended to put these into main themes. I gave a broad overview of some of the comments from their focus group interview and asked them whether they felt I had captured their feedback accurately. In both cases, the participants of the focus groups broadly agreed with my interpretations and were looking forward to the completed thesis-they want to read it!!

3. RESULTS AND INTERPRETATION

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Results and Interpretation

After immersing myself in the data, themes emerged that were clearly linked to the aims of the WDHB education programme and its effect, thus enabling transparent and defensible links to be established between the data and the summary findings (Thomas, 2006).

I was interested in how the themes seemed to me, to fall into a “before and after scenario” i.e. how participants felt before the education programme and then how they felt afterwards. The facilitator was very skilled in ensuring participants discussed the three interview questions with the impact of the education always in mind e.g. so how would it have been before the education or now that you have had the education how has that changed your practice?

I named one theme “Existing Knowledge” as this consisted of sub themes concerned with the knowledge, skills and experience participants brought with them to the Palliative Care education sessions.

The second theme incorporated knowledge and skills acquired as a result of attending the Palliative Care Education Programme and I named this theme “New Knowledge.” Sub themes spoken of by participants included an increase in their understanding of Palliative Care including assessment of symptom management, grief, loss and bereavement and improved communication skills.

The third theme contains all aspects around attitude and behaviour change related to Palliative Care that participants experienced following attendance at the education sessions. All the sub themes in this theme entitled “Attitude and Behaviour change” relate to how participants now think and behave or are more aware than before the education, of Palliative Care and how it relates to them and their residents and families/ whānau.

I will now discuss the results in more detail, taking each of the main themes in turn and supporting them with quotes from the transcripts. A simplified tabulated form of each theme precedes each discussion chapter.

Theme 1 - Existing Knowledge

The first main theme was about staffs' existing knowledge prior to the education delivery. Staff spoke of a range of issues which were identified as themes (see Table 6).

Table 6 - Theme codes for Existing Knowledge (Theme 1)

Sub Themes	Explanation	Frequency of occurrence
Building on existing knowledge and skills	Staff commented that the education reinforced a lot of what they were already doing. The education updated their skills, expanded their existing knowledge.	10
Validation/Affirmation	RAC staff have felt that they have been doing "the right thing," and that the education affirmed and validated these feelings. This was very positive, it made them feel good.	13
Acknowledgement of the Health Care Assistant (HCA) role	This theme is about HCAs acknowledging the important role they have within the RAC facility, particularly with reporting their concerns to the Registered Nurses	2
Benefit of whole team learning together-coming from the same place	In this theme, working together, developing common understanding is commented on by RAC staff.	3

Sub Themes – Theme 1

The main theme was supported by subthemes which overlapped and contributed to each other.

Building on existing knowledge and skills

Some staff stated that they were already doing a lot of things that were covered in the education programme and they had systems and processes in place citing pain assessment for residents with Dementia as an example. Staff spoke of how they had been delivering Palliative Care instinctively for their residents and how knowledge around end of life care in

their facility is passed on from senior or more experienced staff to junior or new staff members. Interestingly, one HCA remarked:

Participant: “It’s the same with the hospital side - basically what we were being taught in the palliative care side we were doing anyway, and the education just reinforced it and made us realise that we were actually on the right tracks, and sometimes it gave us just a few little hints, because some of us have done the palliative care part of the care anyway, although we hadn’t been educated in it.”

Ethnicity: NZ Pakeha. Role: HCA. RAC:PH

Froggatt (2000b) speaks of the importance of understanding the culture of care in a residential aged care facility for education to influence the provision of care. Without a structured approach to Palliative Care education, training and clinical support, the quality of the skills and knowledge passed from colleague to colleague is totally dependent on individuals rather than evidence based-practice. According to Katz (2003) to address the high levels of acuity and complexity of residents now residing in Residential Aged Care (RAC) education is necessary. Caring attributes are not sufficient, new and existing staff need special skills, knowledge and competence in Palliative Care to improve the quality of life for not only their dying residents but those with long term conditions as well (Ersek and Wood, 2008).

Staff in another facility spoke of on-going education already in place but by attending the WDHB Palliative Care Education programme they had been given quite a bit more information to work with, “like building bricks” and that their existing skills had been “sharpened and honed.”

Other facilities mentioned that their knowledge had been expanded, updated or refreshed. Many comments in this sub theme could be linked to other sub themes, Raised awareness of Palliative Care, Improved Assessment skills and the next sub theme to be discussed Validation /Affirmation.

When developing the WDHB Palliative Care Education, the team were keen to recognise the knowledge and skills that participants would be bringing to each session as advocated by Brazil, Brink, Kaasalainen, Kelly and McAiney (2012). This quote demonstrates that the explicit acknowledgement, as the team stated in the programmes aims, was appreciated:

Participant: “I think the education reinforced a lot of what we were already doing, which I think was quite important.”

Facilitator: So affirmed what you were doing was correct, is that what you are saying?

Participant: “Yea – except that maybe we could have done better.”

Ethnicity: NZ European/Pakeha. Role: HCA. RAC: PH

Philips et al., (2006), argue that a failure to value the work of RAC staff sends a message to our communities that as a society we do not value older people and that it is increasingly important RAC care is recognized as a specialty.

This theme has highlighted the issue of how knowledge has been acquired by Residential Aged Care staff around Palliative Care issues. In the absence of evidence based Palliative Care education programmes, care delivery has been instinctive and based on personal experience or that of others. High staff turnover is an issue in this care setting so there are many occasions where information is passed on verbally or demonstrated in practice. Bad practice or misinformation is then passed on and then become indoctrinated into the culture of an organisation. It is very difficult then for new staff coming into the organisation to change practice if it is not appropriate. Senior staff members regardless of their role can be hugely powerful “this is the way it has always been done”.

Validation/Affirmation

This theme is linked to the previous theme “Building on existing knowledge and skills” but staff also spoke animatedly about how the education had validated their instincts and the importance of knowing that they had been doing the right things for their dying residents.

Participant: “I feel that the education training has validated my instincts and given me confidence and awareness that the processes we use are correct.”

Facilitator: thank you - when you talked about validation, can you explain that a wee bit for me.

Participant: “Well I’ve always done palliative care instinctively, you know how we care for our patients, we’ve always taken them to dying as well, and so we were just doing that purely because we love it, so now to actually find out that this is what we do, and what we were doing was right, it’s enriched us more really, yea it’s good.”

Ethnicity: Maori. Role: HCA/Cleaner. RAC: SDU

The media are very quick to report negative actions and conditions in RAC facilities writing very emotively about sub-standard care (Cumming and Johnston, 2012) but it is very rare that the media write about the positive aspects. Judy McGregor whilst working undercover in a RAC facility in her role as Equal Opportunities Commissioner highlighted the poor pay and conditions staff working in RAC have to endure and has made recommendations in her Caring Counts report to the government for pay parity with DHBs (Daniell, 2012). When asked what was the single most important thing she learnt from her experience going undercover as a carer for the elderly? Judy replied, “Enduring emotional attachments that carers develop with, and for, their older clients.”

One staff member from a Rest Home shared the feedback that they had received from a resident’s bereaved son, the resident died shortly after they completed the education programme:

Participant: “I did have remarks with regards to our care which I thought was really complementary, the son was there and you could see he was really dying, and he said, you know he gets much better care here than in the hospital from where he had just come from, and the son was grateful for that, that his father was looked after, it gave him comfort, and it also inspired us to carry on and do these things with a ‘lighter heart’ or whatever you want to call it.”

Ethnicity: European. Role: HCA. RAC: RH.

Rest Homes historically have cared for relatively independent residents. They have a lower ratio of qualified nurses and residents therefore are usually moved to Private Hospital level of care when their conditions become more complex. The OPAL study shows the largest high dependency proportion increase is in Rest Homes from 16% in 1988 to 35% in 2008 (Boyd et al., 2011) consequently, residents in Rest Homes are much less well and the number of deaths occurring in Rest Homes is on the increase. The positive feedback from a relative in the quote indicates that Rest Home staff are capable of providing good quality end of life care providing they have the confidence, skills and awareness of when and how to access available support. The education programme appears to have enabled this process and comments such as “feeling enriched” and having a “lighter heart” indicate that it has also had a positive effect on staff morale through validation and affirmation. There are links to the sub themes reducing personal stress and increased job satisfaction in this sub theme.

It is vital therefore that Rest Home staff in particular are given the opportunity to access education and support so that they have the necessary knowledge, confidence and skills to care for their residents but also know their limitations and when to refer on.

Acknowledgement of the HCA role

There were only a few comments about acknowledging the HCA role and they came from one Private Hospital.

Participant: “I agree with what my colleague said, she said that she had more confidence and also with dedication she was able to apply this learning. Also it acknowledges us health care assistants our part in residents/family care.

Facilitator: Can you give an example of something?

Participant: “Like dealing with the family.”

Ethnicity: Asian Role: HCA. RAC: PH.

“I think we can read the signs a lot quicker, better, we all read the signs anyway, as everybody has said, we work with these people for years on end and know as soon as something is wrong, and it doesn’t have to be an RN to notice it, it’s usually the care givers that actually do notice it first, and let the RN’s know, just we see the signs even quicker, the education has reinforced, these signs are the signs of death.”

Ethnicity: NZ Pakeha. Role: HCA. RAC: PH.

During the literature review there was reference to the HCA role in RAC facilities not being recognised and valued by others, in particular the RNs (Ersek et al., 2000; McDonnell, et al., 2009).

It would appear from these quotes and the absence of comments across the other transcripts that this lack of appreciation does not appear to be an issue for the participating facilities. One reason for this may have been the inclusive nature of the WDHB Palliative Care Education Programme with all staff able to attend (see Benefit of team working together sub theme) and learn together.

Another factor is the positive attitude of the WDHB Gerontology Nurse Specialist Service who supports the RAC facilities across the district. They are strong advocates of the HCA role including them in the development of the Care Giver Guides (www.waitematadhb.govt.nz) which the WDHB Palliative Care Education team actively promoted during each education session.

The quotes relate more to the important role that HCAs now hold in RAC McDonnell et al.,(2009) acknowledge the skill mix in this care setting is weighted towards HCAs and that they have more patient contact than any other discipline, providing the majority of direct care. The HCAs speak of assessment and confidence, both sub themes discussed later and the importance of passing on information to RNs. Froggatt (2000b) found in her study that due to the HCAs lack of preconceptions about education and care delivery, the greatest impact of the education programme she evaluated, was among HCAs.

Residential Aged Care HCAs have a wide, diverse and variability of skill mix and therefore a team approach to care planning and delivery is required in this care setting to optimise quality Palliative Care provision.

Benefit of whole team learning together-coming from the same place

Staff spoke of the benefit of learning together as a team with the majority of comments coming from the smaller facilities. There was some concern initially about having different disciplines in the same group and whether we would be able to manage RNs, caretakers, admin staff as well as HCAs many with English as a second language. The WDH B Palliative Care Education team ensured that the education programme content was inclusive of different roles, we made more detailed hand-outs available to RNs-interestingly the HCAs wanted copies for themselves as well and the case studies generated lots of dialogue across the roles which were very enlightening and informative both to staff and to the Hospice Educators. The ground rules were re-visited at each session to promote a safe environment which encouraged respectful listening, non-judgemental discussions and everyone's' perspectives to be heard.

Participant: "Well it was really good because we did it all together, at first it was just a couple of people but it ended up with basically all of us, as we are such a small group, 6 of us, basically all the staff, and it got them all going and because Claire was very good at getting everyone to communicate and was non-judgemental. But I feel that we are all kind of kicking from at the same level now, knowing what we're trying to achieve"

Ethnicity: NZ European Pakeha. Role: RN. RAC: RH.

This first quote speaks of the benefit of staff being on the same page and having a common purpose or goal. Katz (2003) advocates that training materials are most successful when used with different levels of staff working together and used in-house.

Participant: "I think the other thing is, as the manager, is that it's good that staff have got this, we're all coming from the same place and how we do it. The educator's stuff did have that, inclusive, family, team thing, it was really nice."

Ethnicity: European. Role: Manager. RAC: SDU.

This second quote reinforces the importance of getting the delivery style pitched at the right level. Staff mentioned words like inclusive and getting people to talk but they also spoke of enjoying the time together as a team to discuss issues that they may not normally have made time for, it was a good team building exercise.

It would appear that the 4 x Hospice Educators effectively facilitated the WDHB Palliative Care Education programme, which led to a positive learning experience for participants.

Theme 2 - New Knowledge

The second main theme was about the perspectives of the staff after the education programme. Staff spoke of a range of issues which were identified as themes (see Table 7).

Table 7 - Theme codes for New Knowledge (Theme 2)

Sub Themes	Explanation	Frequency of occurrence
Increase knowledge/understanding	RAC staff spoke about a broader understanding, knowing more now than before, given greater guidance. Not only of the Palliative Approach but symptom management, end of life care and the role of Hospice/Specialist Palliative Care services.	33
Resource to refer back to	This theme refers to comments made by RAC staff about how useful the resources have been for them that were either provided or highlighted as being available to them during the sessions.	3
Grief Loss and Bereavement	In this theme RAC staff spoke much about personal loss and grief. They also spoke of having greater empathy for bereaved family members (including their own) with the new knowledge gained from the education.	12
Advance Care Planning	Staff spoke of the need to formulate a plan of care for the resident that included input from the family/ whānau and other members of the	5

Sub Themes	Explanation	Frequency of occurrence
	Multi-disciplinary Team. Initiating conversations about end of life care	
Dissemination of new knowledge to other/new staff	This theme is about imparting participants' new knowledge to other members of staff-new, junior and/or existing staff, helping with their educational needs.	4
Communication	In this theme, staff commented on how the education helped them in the way they communicated with both residents and their families.	18
Improved Assessment Skills	Staff spoke about improved observation skills, asking better questions and listening more to their residents.	14

Sub Themes - Theme 2

The main theme was supported by subthemes which overlapped and contributed to each other.

Increase knowledge/understanding

Staff spoke of the education being very informative and that it had deepened and expanded their knowledge and understanding. In doing this it had also helped them feel more confident and raised their awareness of the Palliative Approach showing links to other sub themes. They spoke of a greater appreciation of how residents might be feeling when they become symptomatic. How it must feel to be dyspnoeic (short of breath) was one example, “the absolute fear that they may have that the next breath they might not get”. This new knowledge gained from attending the education programme appears also to have caused them to be more compassionate in their care.

Participant: “For me the education gave me a better understanding to care for the resident, and made me more aware of what is happening to them and how to deal with anxiety and I’m kinder to them.”

Ethnicity: Asian. Role: HCA. RAC: RH

There were also examples of changes in behaviour in this sub theme because of the new knowledge gained, linking this to Theme 3. Session 5 covered End of Life Care and we explained to participants that hearing was the last sense to go therefore it is important to be sensitive when speaking to or within earshot, of a dying resident.

Facilitator: Can I just ask you a question – You said that you didn't know that about the hearing, and then you received that education, how did that change your practice?

Participant: “Absolutely, I was so careful, I continued talking to them, because I knew that they could hear, you come in, tell them what you're doing, so they know what is happening.”

Facilitator: And did it make any difference to how you treated the relatives or other staff members?

Participant: “Yes, yes, one was just aware that one was still not dead yet, and they are still here.”

Facilitator: Thank you.

Ethnicity: European. Role: HCA. RAC: RH.

Froggatt (2000b) noted a similar change in the way staff approached residents following participation in a Palliative Care Education Project (Froggatt, 2000a) which RAC staff confirmed was because of an increase in their knowledge and understanding of residents with Palliative Care needs. Stillman et al (2005) suggests therefore that it is essential to sensitize RAC staff to the problems and issues faced in palliative care for their residents, if the quality of end of life care is to be improved.

In the previous Theme 1, Building on existing knowledge and the role of the HCA was discussed. This next quote highlights that RAC staff in particular HCAs, come to the role often with just their life experiences, often having no previous formal education or qualifications to equip them for caring for residents with complex Palliative Care needs (Brazil and Vohra 2005; Katz 2003; Whittaker et al 2006).

Participant: “I’m a mother, and this is my first job as a caregiver – so once I joined (the educator’s) class I knew more – when you are a mother you think you know everything sometimes, but when you go to the class, and I’m not a nurse, I learn more about sickness and the residents, to go forward and to talk to the residents.”

Facilitator- So you said there, to go forward and to talk them, can you explain that a little?

Participant: “Yes, well if they are in pain or anything, so you can talk to them, as a mum you know how to talk to your child about pain, but with the residents it’s different.”

Ethnicity: Asian. Role: HCA. RAC: PH.

This HCA has recognised that the approach required to assess and manage pain with the residents is very different to how she deals with the pain experience of her own child. It would seem that the education has made her more aware of the different approach that would be required. There are links in this quote to other sub themes; Communication, Raised awareness of the Palliative Approach and Improved Assessment skills.

The new knowledge has raised awareness for staff of how much is involved when caring for a resident with Palliative Care needs. The phrase “people do not know what they do not know” is relevant here; the quotes suggest staff now appreciate the benefits for evidence-based education.

Participant: “but now it’s much wider, there’s pain, there’s food, there’s family, there is a whole range of things that we didn’t take into account, and now that we’ve had the sessions we can now say ah well, we’ve covered this and we can add all of these as well, our knowledge base is much much better.”

Ethnicity: European. Role: Manager. RAC: SDU.

Resource to refer back to

Staff spoke of not only having new knowledge and understanding around Palliative Care issues but they spoke of having tangible tools and resources that they could now refer back to as needed following attendance at the WDHB Palliative Care Education Programme. Staff also found the RACIP RN and Caregiver guides a useful resource (www.waitematah.govt.nz), many of them displaying them prominently in their facilities. The Hospice Educators referred to them at each education session to ensure consistency of practice with the Gerontology Nurse Specialist Nursing Service. A blend of Gerontological and Palliative Care expertise, Kristjanson et al., (2005) argue, is needed to meet the needs of the older population and Stolee et al., (2005) advocate access to expert resources and information are important factors in helping to reinforce education programmes.

One facility manager commented on the fact that this programme was the first Palliative Care Education Programme developed and delivered specifically for a Residential Aged Care setting that she had experienced. The literature review showed that there has been a paucity of available Palliative Care Education for RAC staff (Katz 2003; Stillman et al., 2005,) and indeed this was the first initiative of its kind both locally in the WDHB area and nationally, at the time of its development.

Participant: “Quite often you don’t get this stuff, directed at residential care, we’ve all been in the sector a very long time, but this directed stuff hasn’t been around for that long and I think it’s good, I think sometimes you look at stuff on the web and it’s so complicated, and you think how can you deal with it, it’s so cold and clinical, rather than empathetic – [educator]’s is clinical, but it’s got that other nurturing side – I think if you leave out the nurture then you’re not doing palliative care anyway, and [educator]’s stuff did have that, inclusive, family.”

Ethnicity: European. Role: Manager. RAC: SDU.

I note that her facility is a secure dementia unit and I wonder if this has some bearing on her comment. People dying with dementia have been shown to have health needs comparable to those with a malignancy and yet dementia has only recently been recognised as a life-limiting illness (Ouldred and Bryant, 2008; deVries and Nowell 2011). Authors like Small, Froggatt

and Downs (2007) suggest that strong similarities exist between the person-centred approach used in dementia care and the Palliative Approach but unfortunately this population of older adults have not had equitable access to Palliative Care so their needs are poorly addressed (Harris, 2007). The statistics show that in New Zealand in 2011, 48,000 people had a diagnosis of dementia, with 12,000 being newly diagnosed each year and will reach a total of 75,000 in 2026 (Alzheimer's New Zealand 2008). A significant proportion of these individuals will be cared for in RAC facilities and this has huge implications for the future for this care setting.

Woven through the entire WDHB Palliative Care education programme therefore was reference to care of the older adult with dementia with particular emphasis on communication and assessment skills required for symptom management, particularly management of pain.

There is a paucity of available Palliative Care education. This was the first time that a comprehensive Palliative Care Education Programme had been available to all staff in RAC facilities across the WDHB; indeed it was the first initiative in NZ. The impact on those with dementia to transferring to a Hospice should they require Specialist Palliative Care can be traumatic for all concerned. There is a need therefore to up skill staff so that residents with dementia may remain in the familiar surroundings of the RAC facility.

Grief Loss and Bereavement

The staff spoke of having a greater appreciation of the grieving process and how that helped them to understand feelings evoked from both personal and professional loss. There was acknowledgment amongst staff of the strong attachments they develop with their residents. There was also recognition and a raised awareness that the Palliative Approach to care does not stop at death but continues into the bereavement phase. There were links to the sub themes Needs of the family/ whānau and Raised Awareness of the Palliative Approach.

There were many accounts of personal loss with staff sharing emotional stories of a death in their own family/ whānau. It would appear that the WDHB Palliative Care education programme had caused them to reflect on their own personal loss and their coping strategies. One HCA whose son had died of cancer spoke movingly about how she found it difficult to

discuss his diagnosis and poor prognosis with him, preferring to choose denial as a way of coping with this very difficult situation.

Participant - “and after this session, someone else in our family has been diagnosed and it made it so much easier for me to say cancer, before I would have just ignored it, not visiting them, and it’s made my feelings towards my son 16 years ago, and I think myself that he knew, he kept on telling me, mummy you know I’m going to die, if I’d had this session before, I think I could have made it easier for him, because me not talking about it made it difficult for him as well.”

Facilitator – So what you’re saying is its made things different for you this time around?

Participant - Different, yes, I can be part of the conversation, because the education just showed me, they also need to talk about it and their loved ones need somebody to take that weight off them.”

Ethnicity: NZ European/Pakeha. Role: HCA. RAC: PH.

Explaining different models of grief during the WDHB Education Programme also appears to have helped staff understand that grief is a very individual experience and that there is no right or wrong way to grieve. The education also served to give more updated information to staff on current thinking around models of grief. One RN thought that grief involved stages that had to be passed through and this was how she was dealing with her own grief from both a personal and professional perspective. Current research promotes continuing bonds with the deceased, grief is now defined as a process of adjustment to a loss and some grief may never be completely resolved (Dent, 2005). This RN stated she had gained personal comfort from this new information she obtained from attending the WDHB Palliative Care Education Programme. Another staff member commented on the delivery style of the education during the session on Grief, Loss and Bereavement, she found having the information presented in person much more valuable than just looking it up in a book or on the internet.

Wowchuck et al (2007) argue that the attitudes and beliefs of staff about death and dying affect the way they provide care to dying residents and therefore any educational initiative

must include explorations of self-care, mutual support and resolution of issues of loss and grief.

The final aspect in this sub theme has been documented in the literature many times and that is about the attachments RAC staff form with their residents and their families (Ersek 2000; McDonnell et al., 2009; Whittaker et al., 2006). Staff realised they said, that they become attached to residents in their care. Having a better understanding of how grief and loss affects individuals through participating in the education programme, they could now relate this to the feelings they were experiencing when a resident dies.

Staff spoke of attending the funerals of residents who had died in their care whenever possible and supporting relatives who returned to the facility following the death of their family member, both of which were aspects of their roles that they felt were very important and therefore always tried to make time for.

Managing successive losses, particularly for those in the busier Private Hospital settings where more deaths occur is an issue for ongoing attention in educational programmes and practice. Due to the specific acknowledgment of the death being undervalued, there is an increasing need to include rituals around death and dying. This would enable some closure for staff along with support mechanisms particularly de-briefs following a difficult death.

Advance Care Planning

Staff in this theme spoke of planning care, managing processes and initiating conversations around end of life care issues with both residents their families and other members of their multi-disciplinary teams. Increased confidence, Needs of the family/ whānau, Increased knowledge/understanding and Improved Assessment skills were all linked to this sub theme.

The Palliative Care Approach encourages early identification of problems therefore advocating a more proactive approach to care rather than crisis management for people with Palliative Care needs (WHO, 2008). One RN explained that following the education, her team now regularly take time to discuss the plan of care for each resident, so the team have a clear understanding of the goals of care.

Froggatt, Vaughan, Bernard and Wild (2009) suggest that the way in which care is planned in RAC is so important as it sets the foundations upon which care planning at times of serious illness, or at end of life, is based. This concept has been taken a step further by the Ministry of Health in New Zealand with the development of the Advance Care Planning (ACP) cooperative (www.moh.govt.nz). ACP is a process of discussion and shared planning for future health care between an individual and a health care professional (family can be involved as well). It assists the individual to identify personal beliefs and values that are then incorporated into that future care plan. Underpinning ACP is the value of the shared understanding that occurs during this process, it is not outcomes driven.

Participant: “My role as a nurse I think it has deepened my knowledge, like maybe you can direct the attention of the doctors or the attention of the family that it’s about time to look at a care plan. It’s more use for looking at what decisions have been made directly for end of life, looking at quality of life, with ongoing treatment. The education gives me the confidence at multidisciplinary teams – starting conversations, but also with the families, respect the residents wish and basically depends on what are we going to achieve from here are we still dealing with the quality of life or are we going beyond what’s been decided.

Facilitator- And you feel that the education has allowed you to do that?

Participant: “I think that assessment that we’ve been hearing a lot here, good assessment takes you along to a conclusion.”

Role: RN. Ethnicity: Pacific Island. RAC: PH.

This new initiative was highlighted during the WDHB Education Programme and it would appear that the new knowledge gained by staff has not only improved confidence to initiate conversations with fellow professionals but be inclusive of family members in the decision making process. Engaging residents and families in care planning discussions, enables them to be better informed and prepared for changes in residents’ clinical status Philips et al., (2008).

Advance care planning conversations should help reduce the number of inappropriate hospital admissions of residents from Residential Aged Care facilities.

Dissemination of new knowledge to other/new staff

This theme had salient specific comments from staff, both of them from senior RN positions and representing one Private Hospital and one Rest Home. Again, links here to other sub themes are identified such as Increased Knowledge/Understanding, Acknowledgement of the HCA role and Raised Awareness of the Palliative Approach.

Participant: “For me, like with the new staff, I can share and educate them, how to deal with residents with palliative care needs, it gives me more knowledge and information on how to talk to them. It helps me educate the new staff.

Ethnicity: Asian. Role: RN CN. RAC: PH.

Participant: “also being able to impart to the care assistants and the others the importance of reporting things, because we rely very heavily, if we are not at the bedside or dealing with the day to day cares, on our health care assistants reporting things, pain, anxiety, anything that might actually improve their quality of life and dying, so that to me was quite highlighted our awareness of that and being able to pass that on.”

Ethnicity: NZ European/Pakeha. Role: RN. RAC: RH.

Having the WDHB Palliative Care Education programme available to all staff allowed many of the team members from each RAC facility to attend. There were of course always some who had to “cover the floor” but this was usually rotated to ensure fairness or some Managers used temporary staff to cover. Holding the education on site also enabled more staff to attend. I believe this theme may have had more comments if we had restricted attendance to a single discipline e.g. only RNs. Our contract however with the WDHB was to be inclusive of all RAC staff both clinical and ancillary.

The literature makes some statements around nurses’ poor dissemination skills, that they are not good at passing on information (Hasson et al 2008). All the more reason therefore to be inclusive to all staff as advocated by Katz (2005).

In order to deliver real and sustainable changes in practice and enhance the quality of care, a Palliative Care “Champion” may be needed. A staff member with a passion for Palliative Care but who has a recognised responsibility and is accountable to disseminate and support evidence based Palliative Care practice within the Residential Aged Care facility.

Communication

Staff in this theme spoke of communicating with residents with dementia, increased trust/openness and having more confidence when speaking with families. They spoke of the WDHB Palliative Care Education Programme being good because it helped them in the way they communicate with residents. I was really interested in this following quote by a cleaner who works in a large Private Hospital. There are links to the sub theme, increased job satisfaction in this quote.

“In my role I go into everyone room and it’s not just going in there, do my work and go out, you have a conversation with them, ask them how their day is going, how are they feeling, it sort of makes their day much better when they have someone to talk to, it makes you feel happy, that you’ve made someone feel happy.”

Ethnicity: Other/South African. Role: Cleaner. RAC: PH.

If the WDHB Palliative Care Education programme had restricted attendance to clinical staff only, roles like cleaners, caretakers, kitchen staff and administration would have been excluded from participation. All these ancillary staff actively took part in the case studies, offering their views about care of their residents. The only research study in the literature which included RAC ancillary staff was a study looking at knowledge and attitudes to Palliative Care in Australia by McInerney et al., (2009). Findings from this were around communication issues leading to poor teamwork and a lack of cohesion for enacting the Palliative Approach. I delivered over 150 individual education sessions and not once did I receive a negative verbal comment or written feedback on the evaluation sheets about having such a wide skill mix in the groups, in fact I had more positive comments about how much they got out of listening to others perspectives.

Other comments were around specific communication skills and most were concerned with answering questions from relatives and fearing that they might say the wrong thing.

Participant: “I didn’t feel equipped well to deal with the families, at such a hard time. I felt limited in what to say and how am I going to answer their questions, and it’s been a challenge for me, but I’m so glad nowadays, I think I know what I’m doing now, more confidence and I’m not nervous about it anymore, because of what I’ve learnt from the training, I’m ready – we joked around with the others, I can say BRING IT ON!”

Ethnicity: Pacific Island. Role: RN. RAC: PH.

It seems that the WDHB Palliative Care Education Programme has given staff extra confidence and some communications skills to help them deal with sensitive situations like this quote;

Participant: “communicating with the family when their relative is dying, it is very hard to comfort them, a while ago someone asked a staff member when is my Mum going to die, but I’m nervous to say what I think to them, [the educator] discussed that with us and if that question is put to you, she said what you say to them was ‘what do you think?’ to the family and put the ball back into their court, to get you out of that, how do you know, nobody knows.”

Ethnicity: European. Role: HCA. RAC: RH.

Others spoke of feeling more at ease with residents with behavioural problems/dementia where before the education they would have avoided them because they were scared. They spoke of the need to invite their confidence, be more patient with them and just sitting with them and listening.

One senior RN spoke of a bit more information flow since the education and she thought that there was more trust and possibly more communication with the family as well and this comment was backed up by one of the HCAs in that RAC facility. Finally in this sub theme, staff spoke of the importance of communicating with the Dr that supports their residents and ensuring that they keep him/her up to date so everyone knows and is on the same page. Ersek

et al., (2000) found that communication difficulties were a recurring theme in their study involving RAC staff particularly between physicians and RNs. There was no specific mention of difficulties from the focus group participants but RNs during the education sessions cited some examples. This theme is linked to almost all of the other sub themes.

Good communication skills are vital and underpin the philosophy of the Palliative Care Approach. Now with the roll out of the Advance Care planning initiative, it is even more important that Residential Aged Care staff strive to improve their skills and include the family in the care planning process.

Improved Assessment Skills

The comments in this sub theme ranged from an improvement in listening skills and general observations through to more specific symptom assessments. There was also recognition that these newly acquired skills were not only useful for dying residents but that they were easily transferable to all other residents with a variety of co-morbidities. Interestingly there was also acknowledgment that assessment did not stop as someone was actively dying, but it was a continual process that continued until death.

This sub theme was also linked with many other sub themes including Increased confidence, Increased knowledge/Understanding and Communication.

Participant: "I think it's made me listen more to the resident, instead of thinking I know what they want, see what they want, asking questions and listening to what they want."

Ethnicity: NZ European/Pakeha. Role: HCA. RAC: PH.

During the case studies it became clear that some of the participants made assumptions about how a resident might be feeling. This was particularly relevant when assessing someone's pain. However, by attending the WDHB Palliative Care Education Programme, it would seem that they are now more aware of the complex nature of pain assessment, that it is a very

subjective experience and that they are more thorough with their assessment skills following their new knowledge as this next quote highlights.

Participant: “Yes, before I said they were just in pain, but now I assess what pain. It’s what the residents say, they are in pain, but for you as a RN it helps to realise that are they having just physical pain or emotional pain?”

Role: RN Charge Nurse. Ethnicity: Asian. RAC: PH.

The literature has presented negatively about staff in Residential Aged Care facilities particularly around assessment of pain and other symptoms (Ersek et al., 2000; Kristjanson et al., 2005; Miller and Mor, 2002; Parker-Oliver, Porock and Zweig, 2004).

Brazil et al., (2012) in their study found that pain assessment and management can be challenging for RAC staff due to the high prevalence of cognitive impairment amongst their residents and the lack of appropriate assessment tools. They also argue that without adequate knowledge and skills, RNs are ineffective at managing pain and other Palliative Care symptoms. We gave every participant a copy of the Abbey Pain assessment tool (Abbey et al, 2004-for assessing pain in residents with cognitive impairment which measures behaviour changes) and spoke at length about the holistic assessment of pain during the WDH Palliative Care Education Programme. This appears to have been taken up by participants in these focus groups.

This quote below shows how a HCA with her new knowledge has enhanced her communication and assessment skills, has realised the importance of good assessment skills and passing on that information.

Participant: “Yes – I feel I’ve learnt to ask better questions – if that makes sense.

Facilitator - Are you able to explain that a bit more?

Participant: “Well, before I begin I like to know/ask not just how is the resident, then be told, oh their fine or whatever, I want to ask questions like when were they last toileted, when were they last turned, are they eating /drinking/

mobilising, have they had visitors, what their mood is like, questions like that, better questions than before.”

Ethnicity: NZ European/Pakeha. Role: HCA. RAC: PH.

Not only has this HCA grasped the importance of being more thorough and undertaking a holistic approach to a Palliative Care assessment but she has acknowledged the importance of passing on that information to the RN. The supportive role of the HCA to the RN is vital as mentioned in the sub theme, Acknowledgement of the HCA role.

Staff commented on the fact that since the education, more things seemed to be looked at and not just with people towards the end of life but everyone’s general well-being so they spoke of the holistic assessment having a much wider application. There appears to be an understanding through this new knowledge that RAC staff can utilise the Palliative Approach which promotes accurate and holistic assessment across all disease trajectories and benefit all residents in their care.

The primary goal of a Palliative Care assessment is to identify the needs of the individual. With most residents residing in Residential Aged Care living with life-limiting illness, it is very important that staff understand the application of the Palliative Approach so that it encompasses chronic illness and is used much earlier, in a resident’s disease trajectory. It appears that many of the reflections of the participants indicate that their views in the area of assessment of the patients have moved as a result of the programme.

Theme 3 - Attitude and Behaviour change

The third main theme was about the perspectives of the staff after the education programme. Staff spoke of a range of issues which were identified as themes (see Table 8).

Table 8 - Theme codes for Attitude and Behaviour change (Theme 3)

Sub Themes	Explanation	Frequency of occurrence
Raised awareness of Palliative Care	The staff spoke of having a better perspective of what the Palliative Approach involves, viewing residents holistically not just physical beings.	33
Increased confidence	This theme is about how the education improved the confidence of staff, to cope with situations that before the education they may have avoided. Confidence was also linked to many of the other sub themes.	25
The needs of the family/whānau	This theme is about how the education had raised awareness of the needs of the family/whānau.	28
Cultural Awareness	Staff spoke of the importance of acknowledging their own personal beliefs and values. To then be respectful of others whose values may be very different to their own.	6
Improved my way/changed my outlook/made me think	This theme is about the way participants viewed residents and situations differently since the education. They explained that the education caused them now to think rather than doing things automatically for residents as they had done previously.	12
Increased job satisfaction	Participants talked about delivering better care since the education for people with Palliative Care needs. Using a holistic approach made staff feel more fulfilled.	8
Reduces personal stress	This theme is about how the education helped reduce fear and anxiety for some participants who prior to the education, found caring for the dying very stressful.	4

Sub Themes – Theme 3

The main theme was supported by subthemes which overlapped and contributed to each other.

Raised awareness of Palliative Care

Staff spoke in this theme of having a better perspective of what the Palliative Approach involves, viewing residents holistically not just physical beings and that it was not just for dying residents. They spoke of having a better understanding of Hospice and Specialist Palliative Care services and that for some staff not from Western cultures; this was something unfamiliar to them. There were links to other sub themes such as Cultural awareness, Assessment skills and Increased knowledge and understanding.

This fits with literature indicating that the term Palliative Care is poorly understood (McIlfatrick, 2006) and there is no widely accepted definition of exactly when a Palliative Care approach is appropriate or what precisely it comprises in relation to Residential Aged Care facilities (Parker and MacLeod, 2002). Historically it has been thought to comprise solely of terminal or end of life care and care that only a Hospice provides. Hospice tends to be thought of as a building rather than a philosophy of care and admission to this building leads to death. However, Palliative Care is accessible to all those and their families/ whānau living with a life-limiting illness, regardless of their care setting and starts at the point of diagnosis of the life limiting illness, sometimes many years before death occurs (Scott, Kendall, Boyd and Sheikh, 2005). Many residents in Residential Aged Care facilities have Palliative Care needs but staff have not always recognised this because of a number of factors, one of these is described in this quote:

“I didn’t know what Palliative care was until I came to the education.”

Role: HCA. Ethnicity: Fijian Indian. RAC: RH.

Another factor is concerned with culture and ethnicity, as mentioned in the literature review, Palliative Care is a Western concept and many of the participants of the WDHB Palliative Care Education programme, identified with non Western ethnicities.

“I think my view is a little bit different due to the cultural difference, I didn’t know about hospice I thought hospice was just the op shop, but when (educator) came with the education, well yea, I knew about hospice, and I thought there were so many good people in New Zealand, different from my own country. The education has made me a little bit more confident in the western way, most Asian countries don’t have this kind of help and I felt very envious. We also didn’t know how to build up our normal life when we are looking after somebody, but here they show you how to build up your life and validate it when you are in that situation, your quality of life.”

Ethnicity: Asian. Role: HCA. RAC: RH.

From the demographic forms 7 participants identified with NZ European ethnicity from a total of 26 participants. The largest proportion were 12 participants who identified with Asian ethnicity and as this quote suggests, may be unfamiliar with the concept of Hospice and Palliative Care. Cooper and Glaetzer (2004) highlight that the Palliative Care Approach is a Western concept and therefore does not have universal application or interpretation. They speak more from a patient’s perspective however, who is from a non Western culture as opposed to a staff member’s perspective who may be from a non Western culture and not comfortable adopting a Palliative Care Approach when caring for residents with Palliative Care needs. There was no evidence across the transcripts of this issue but during the case studies, there was much discussion around cultural considerations when delivering the Palliative Approach to Care for residents of different cultures by culturally diverse staff.

With such diverse cultures and ethnicities represented in Residential Aged Care staff, Hasson et al. (2008) found in their study that English as a second language proved to be a challenge as did McDonnell et al., (2009). The results of the Learning Needs Analysis informed the WDHB Palliative Care Education team that 40% of staff surveyed had English as a second language so we were mindful to ensure the content and delivery style took this into consideration. We had no feedback from participants about not understanding the education programme content.

Staff spoke of having a better perspective, being more prepared and therefore more supportive of residents’ needs since attending the WDHB Palliative Care Education. This change in

attitude by staff appears to have been as a result of a Raised Awareness of the Palliative Approach which promotes the early identification of problems (WHO, 2002).

They also stated the education programme had given them a more holistic view of the resident instead of just looking at their physical needs they now looked at their emotional and spiritual needs as well. The definition of Palliative Care which promotes care of the whole person was shown at every session and referred to throughout the programme. The literature supports these findings from the focus groups, that Residential Aged Care staff are unaware of the principles of Palliative Care (McDonnell et al., 2009; Katz et al., 1999 and 2003; Wowchuck et al., 2007).

Part of the education programme involved discussing who delivers Palliative Care, and referral criteria to Specialist Palliative Care /Hospice services. Specialist Palliative Care is a relatively new speciality and with any new speciality comes the need to define roles and responsibilities and referral criteria. Increased understanding of the Palliative Care approach and its delivery means that staff in Residential Aged Care facilities will be able to make informed choices. Across the transcripts there was no evidence of referring residents to Hospice services but there were examples of personal experience with a family member diagnosed with a life-limiting illness and how the education had informed the participants about how Specialist Palliative Care services like Hospice could help/advise the person with the illness and the family/ whānau. To help build relationships and demonstrate availability of clinical support from the local Hospice, the Community Palliative Care (CPC) nurses came along to some sessions in order to introduce themselves to the Residential Aged Care staff. This was found to be beneficial for both teams and was also important for on-going sustainability of the new learning as the clinicians would need to “walk the talk” thereby embedding the new learning into practice (Froggatt, 200b).

Finally this is an example of a behaviour change around the Palliative Approach to care, following the education programme by a HCA in Private Hospital.

Participant: “When I worked in Australia, as a care giver, we had an Aromatherapist, who made up a Palliative Care Basket, which I have made here with things for anxiety and stuff, spray for the room to help the resident and the relatives, and religious item, also nice smelling things to wash the patients with,

because there is smell, especially when the resident is dying, and a lot of residents families can't cope with that, all they can smell is the dying process, so this sort of hides it, but having the education made me remember that in Australia and I suggested it to (Clinical manager), and I made one up, and we've used it a few times – it's nice and relieves the resident and the families.”

Ethnicity: NZ European/Pakeha. Role: HCA. RAC: PH.

Nolan and Featherstone (2003) remark that adopting the Palliative Care approach relies on the integrity of staff, many of whom are unqualified carers. They argue it is essential that this integrity be nurtured and supported at institutional level and by investment in Palliative Care education which will not only provide better symptom management for Residential Aged Care residents but also greater awareness of the needs of residents and relatives.

Building and maintaining relationships between Residential Aged Care staff and both Specialist Palliative Care and Gerontology Nurse Specialist teams are vital. The clinical support from the Specialist teams re-enforces the new learning and helps translate the theory into practice. Attitudinal and behavioural changes are more likely to be sustained with positive role modelling and mentorship by these Specialist clinicians.

Increased confidence

This theme has links to many sub themes including Communication, Assessment skills, Needs of the family/whānau and Increased job satisfaction. Staff across all five focus groups spoke of having increased confidence following the education whether it was around communication, dealing with families or feeling more confident knowing that they have more knowledge, awareness and understanding of the Palliative Care approach.

Increased confidence led to changes in behaviour as demonstrated in this quote:

Participant: “Yes confidence has definitely improved, because even amongst the staff we feel much more confident in discussing things, like before, you'd know that person was sick, but none of us would dare suggest the resident was dying,

yet we've had an incident where a gentleman who was with us, like was said, you could smell it, we could openly talk about it, it was almost not your right to say he was dying, but now we can openly say, hey look I think he won't be here for much longer, that smell is opening telling me that he's going – before we would never have done that – so amongst the staff it's given us that confidence that we can discuss and talk about it.”

Ethnicity: European. Role: HCA. RAC: PH.

This demonstrates that the education not only empowered the staff by giving them more confidence but it also acknowledges that the HCA role is integral in recognising the dying process in a resident. Not only are they the first in the multi-disciplinary team to notice changes in a residents condition because they deliver the majority of direct care but this quote suggests that they also have the skills and understand the importance of passing on this information to senior team members. Once someone is diagnosed as dying, there is a shift in the goals of care from quality of living to quality of dying, this was covered in the education programme as well as how to recognise signs of deterioration and actively dying. McDonnell et al., (2009) found similar challenges when analysing education needs for RAC staff. There were issues with some HCAs not wanting to be perceived as stepping outside role boundaries and this was linked to lack of education and confidence.

Other comments included staff feeling more confident to ask for help with the management of their residents with Palliative Care needs. This particular change in behaviour is quite significant. Findings from the literature show that staff in Residential Aged Care facilities, although aware of the local support available to them from Hospice (Specialist Palliative Care) teams, do not readily refer residents to them. It would seem that by attending the WDHB Education Programme, staffs behaviour has changed, they feel more confident to ask for help which also implies they are more aware of their limitations.

This next comment shows links to Theme 2 – Communication.

Participant: “The education gives me the confidence at multidisciplinary teams-starting conversations.”

Ethnicity: Pacific Island. Role: RN. RAC: PH.

Philips et al., (2008) found that Palliative Care education increased RAC staffs' personal confidence by equipping them with the specialist language of Palliative Care enabling them to join in conversations on more of an equal level with other providers e.g. GPs and Hospice teams.

Increased confidence impacts on many of the themes discussed across the transcripts. It was referred to frequently by staff and attributed to participation, in the WDHB Palliative Care Education Programme.

The needs of the family/whānau

This sub theme was probably the one I was least expecting perhaps because I assumed families/ whānau were automatically and actively included in resident's care. The theme occurred across all 5 focus groups and was linked to many other sub themes including Changed my outlook, Raised awareness of the Palliative Approach, Confidence, Communication and Increased knowledge/understanding. There was a real sense from the staff of not appreciating just how much families/ whānau were affected by their relative's illness. Staff spoke of being more proactive, seeking family/ whānau members out, not avoiding them particularly at night. They also spoke of including them in the caring process, right from admission to their facility.

The education team were mindful that one of the main concerns raised in the Learning Needs Analysis feedback for Residential Aged Care staff, was dealing with families/ whānau. During the WDHB Palliative Care Education Programme therefore, we discussed the challenges of family members having different emotional timetables and their subsequent coping strategies that they adopted to deal with the stress and impending loss of their relative.

Participant: "I think one of the main things I learnt on the course was it's not just about the residents it's their family as well and how they cope with it."

Ethnicity: NZ European/Pakeha. Role: HCA. RAC: PH.

Staff spoke of the importance of involving the family/whānau from the beginning to build good relationships and keeping them informed particularly when there were changes in resident's conditions.

This quote demonstrates a change in behaviour for one staff member who would have avoided interaction with families/ whānau prior to attending the education programme.

Participant: “when the family is there, because you don't know how to act, because how desperate they are. I found out later with the training, just to be there, ready to help, just to make everything clean for them, offer family refreshments and so on, and not just stay in the station, and only go there when it was really necessary.”

Ethnicity: Asian. Role: HCA. RAC: PH.

The role of the family/whānau in RAC settings is significant and a death is almost always a family event Hasson et al., (2002) argue. Expectations of family members can be prominent factors in influencing the care provided and although families may have delegated the role of physical carer to the RAC staff, Hasson et al., (2002) further suggest that they have not relegated their role as a family member. The family/ whānau will need to be incorporated in the decision making process, particularly at end of life. Much in the literature states that RAC staff have not been good at involving families/ whānau in the care of residents with Palliative Care needs (Curry 2009; Froggatt 2000b; Philips et al 2008; Stillman 2005) leading to frustration, complicated grief reactions from bereaved relatives and emotional stress for RAC staff. It would appear that the WDHB Palliative Care education programme has enlightened staff to the principles of the Palliative Approach which sees the inclusion of family/ whānau and friends as an integral part of care provision (Katz et al., 2001).

Encouraging the families/whānau involvement in their relative's care and equipping Residential Aged Care staff with the communication skills, increased confidence and a better understanding of the Palliative Approach may lead to more therapeutic relationships and ultimately better care outcomes for residents across the disease trajectories.

Cultural Awareness

Staff spoke of having a raised awareness of cultural issues, an understanding of the Western way from some staff of non-Western cultures and interestingly staff made specific reference to one case study involving cultural issues. This theme was also linked to Communication, Raised awareness of the Palliative approach, Confidence, Needs of the family/ whānau and Increased knowledge/understanding.

Staff said the education was informative and had reminded them of the importance of looking from another's perspective not just their own. They understood now that residents and families/ whānau from different cultures to their own should be treated with respect and they saw the need to build up trusting relationships and they spoke of wanting to do something for them. This following quote is one example of a change in behaviour around cultural awareness.

“For me the training has given me a more holistic view of the residents. Look at their culture, especially – their culture may be different to mine so I have to learn all about that and treat them from that aspect, talk to their family, ask them what they like, just look at the whole picture more.”

Facilitator – Can you give me an explanation or extend a wee bit further as regards to culture, if you can give us an example or something?

Participant: “Maybe food, it might not be in their culture to eat what we give them, it might be something else, and I can put a request into the kitchen to get something they would like.”

Ethnicity: NZ/European Pakeha Role: HCA RAC: PH

The case study referred to in the next quote, was used to try and encourage Residential Aged Care staff not only to look at holistic pain assessment but to also think of creative ways to care for residents with specific needs. Although this particular man is from Samoa, we emphasised that the principles of his management are transferrable to any culture.

Participant: “With the classes and stuff, I remember when (the educator) was talking about, the Samoan guy who would have liked to go home to die, but couldn’t, so what do we do for him, well we bring Samoa to him, and we can suggest things like that, if someone is from another country we say is there anything you want to bring in for your mum/dad.”

Facilitator: So you wouldn’t have seen that before?

Participant: “We wouldn’t have been brave enough to actually suggest it, we would feel that we were stepping on toes, but now we’re sort of a bit more confident in our suggestions, because we know they are the right suggestions.”

Ethnicity: NZ European Pakeha. Role: HCA. RAC: PH.

It would appear that the education has empowered this HCA and this has resulted in an attitude and behaviour change. Curry et al., (2009) found similar outcomes, involving Residential Aged Care staff in education resulted in them feeling more empowered and more confident in their ability to assess and manage symptoms such as pain. In this quote there is a link to the sub theme acknowledgement of the HCA role. The HCA mentions “stepping on toes” indicating that there could be some role boundary issues. McDonnell et al., (2009) found similar issues with HCAs unsure of their communication role, not wanting to encroach on the RNs’ role and they also found HCAs were influenced by the culture of care in the organisation. One solution offered by Hancock, Campbell, and Ramprogus (2005) would be the development of explicit policies in relation to roles but suggest these would need to be formalized in consultation with HCAs and their colleagues.

The WDHB Palliative Care Education team purposefully chose to use case studies from their experience to make the learning as real as possible for participants. There was reference made to the case studies by staff throughout the transcripts, elements obviously remembered and reflected upon. The education team had woven in cultural considerations throughout the case studies with the aim to raise awareness of the different beliefs and values of cultures within New Zealand in relation to Palliative Care. There are good cultural resources available to health care professionals in WDHB (www.caldresources.org.nz) and these were highlighted to participants. However, a cautionary note was always given to staff when assessing cultural

needs of an individual- ask, never assume. Cooper and Glaetzer (2004) remind us that cultural considerations are integral to the assessment process. They caution us to not assume that all members of one particular group however, share the same values and beliefs hence the importance of an individualised approach to care.

This theme has raised several issues- the culture and ethnicity of the individual and their specific needs, organisational culture and the role boundaries and expectations particularly of HCAs.

Improved my way/changed my outlook/made me think

Staff in this theme spoke of an improved way with the resident, that they were looking at residents differently and from all angles. They stated that the care they deliver had changed because they were better informed and more aware since participating in the education sessions. There were links to the sub themes Raised Awareness of the Palliative Approach and Increased knowledge/Understanding. One cleaner explained that her outlook had been changed and she was now trying to improve the housekeeping standards within her facility for residents, visitors and staff. Other comments included staff recognising that their practice, prior to participating in the education, had become automatic:

Participant: “Yea - you do things automatically all the time, without really thinking about it but I think the course has made me think about things.”

Ethnicity: NZ/European Pakeha. Role: HCA. RAC: PH.

Phillips et al., (2007) highlight that it is rare that behaviour change occurs solely through the acquisition of new knowledge and advocate therefore that Residential Aged Care staff need to be provided with opportunities to explore their own values and attitudes to a range of issues related to end of life care.

Participant: “It’s made me more aware of my attitude to dying, and my abilities and belief systems In actual fact, in my view it isn’t just palliative care, because I think that the education we got from (educator) has really made us look at the

clients differently, because our clients are very old and very fragile, and very disordered, the stuff that is in the palliative care document, can actually help us with anybody else, not just the care of the dying.”

Ethnicity: NZ European/Pakeha. Role: Manager. RAC: SDU.

This quote not only suggests that the education has made this facility manager more self aware but that she is looking at residents who are not actively dying within her facility differently, that might benefit from the Palliative Approach. This is particularly pertinent as this manager works in a secure dementia unit where all the residents have severe dementia. They would therefore be classified as having a life-limiting illness thereby qualifying according to the WHO definition, to the Palliative Approach (WHO, 2002).

Sensitizing staff in Residential Aged Care facilities to the problems faced by residents with Palliative Care needs, is thought to be essential to improving the quality of care provision (Stillman et al., 2005).

Increased job satisfaction

Staff in this theme spoke of feeling more fulfilled, having a lighter heart and taking pride in the care they deliver for residents with Palliative Care needs. Following a conversation that affirmed and validated their holistic approach to care for their residents and families/whānau, one RN commented:

Facilitator: so how did that make you feel?

Participant: “Pretty good – yea, yea, we always provide holistic care here, we like to do all the whole thing, it’s lovely to have that extra input and if we could go the extra mile, we would.”

Ethnicity: NZ/Pakeha. Role: RN. RAC: RH.

This quote shows links to other sub themes Grief, Loss and Bereavement and the Needs of the family/ whānau:

Participant: “Oh yes, I take pride, I feel really good, when a resident’s dying and you see them go through right to the end and with the relatives to, and you can comfort them as well, I think that’s so important, it doesn’t just stop there, when the resident dies, because the relatives come in and I just like that part of it.”

Ethnicity: Maori. Role: Admin. RAC: RH.

Cohen, O’Connor and Blackmore (2002) looked at attitudes of staff in Residential Aged Care and found that those currently delivering Palliative Care held more positive attitudes to their work than those who did not and those positive attitudes were likely to be reflected in the care provided.

I note with interest that this quote is from an administrator in a Rest Home facility. She speaks proudly of being involved in the dying process for residents and also acknowledges that care does not stop at death but continues into bereavement for the relatives. It would appear that she feels a part of the clinical team supporting the resident on their disease journey and this for her is a positive experience. This is an example of the importance of delivering Palliative Care education to all staff in facilities, not just those clinicians involved in direct care (McInerney et al., 2009).

Reduces personal stress

The staff spoke in this theme about not avoiding the dying person, not being so afraid and of reduced levels of stress. There are links to many sub themes including Needs of the family/whānau, Communication and Increased confidence.

Participant: “ but now I work I’m not afraid of being exposed to family, and talk to them and when the dying happens, I was ready and able and not stressed, something not to be afraid anymore.”

Ethnicity: Asian. Role: HCA. RAC: PH

The WDHB Palliative Care Education programme content detailed the dying process and helped staff to recognise the signs and symptoms of imminent death of a resident. It is usually

the HCAs that notice these first changes in a resident's condition (as mentioned in sub theme Acknowledgement of the HCA role) because they provide the majority of direct care. This HCA also mentions being exposed to the family/ whānau which infers that she may be feeling vulnerable. It appears that the education has given her the confidence to communicate with the family/ whānau, prepared her which has lessened her personal stress.

This last quote demonstrates behaviour change by not avoiding someone who is dying.

Participant: "most of all I find it (the education) very useful in reducing my stress caring for dying residents because before when someone was dying I would avoid as much as possible going to them."

Ethnicity: Asian. Role: HCA. RAC: PH.

The staff member does not elaborate why she would have avoided them and this is something that Wowchuck et al., (2007) found in their review. Fear, they found, is a commonly expressed reaction of RAC staff caring for the dying but the source of the fear is not always clearly articulated in studies. I am interested to note that 3 out of the 4 quotes in this theme are from HCAs who identified with Asian ethnicity. I wonder following the quote from a staff member in Theme 2, if their previous fears and avoidance of the dying resident and their families/whānau stems from their cultural belief system.

Whittaker et al., (2006) offer a way to reduce staff stress. In their study they found participants found it easier to approach residents and their families/whānau if they had built up a relationship with them.

Underpinning the Palliative Approach are those components essential for building and maintaining therapeutic relationships. Good communication and assessment skills, an understanding of the holistic approach, inclusiveness of family/ whānau and respect for cultural differences.

In summary, using the general inductive approach, themes emerged that were clearly linked to the aims of the WDHB Palliative Care Education programme and its effect.

4. CONCLUSION

Main Findings

The impact of the WDHB Palliative Care Education Programme was that it made Residential Aged Care staff think differently about their residents. They had a greater appreciation of the Palliative Care approach, that it was about holistic care and this meant that their views about assessments would be more likely to take into consideration resident's physical, emotional, cultural and spiritual needs. Participant's reported recognition of the cultural considerations of both staff and residents and that individual's values and beliefs were unique and needed to be respected. They also saw a much wider application of this approach to include other residents with chronic illness and its use much earlier in a resident's disease trajectory, not just restricted to end of life care for those with a malignancy. The greatest awareness raising was around the needs of the family/whānau. It was as if staff knew that family/whānau needed to be involved in the planning and delivery of care for their relative but that the staff had lacked an understanding of just how integral their role was for the resident. After attending the education sessions, staff reported pro-actively engaging in conversations with family/whānau helped by an increase in confidence with their communication skills and a better understanding of family/whānau different coping strategies.

The WDHB Palliative Care Education programme was well received by Residential Aged Care Managers and staff for two reasons. Firstly, the Learning Needs Analysis was seminal in directing the content and delivery style with the case studies in particular felt to be an effective teaching method engaging staff of mixed roles and abilities. Secondly, by acknowledging the existing knowledge and skills of Residential Aged Care staff, the WDHB Palliative Care Education programme affirmed and validated current practices. However, staff had the self awareness to know that they could do better.

This research study has shown that there has been a behavioural and attitudinal shift in staff and this was demonstrated throughout the transcripts in how staff spoke and felt about the impact of participating in the WDHB Palliative Care Education programme. Staff spoke of not avoiding residents who were dying, being kinder to them and less fearful of actively engaging with them and their family/whānau. Asking better questions which led to improved assessments of residents and family/whānau needs.

Some reported practices have changed so it is likely that the quality of care for residents and their family/whānau has also changed.

Significance of findings/ Main literature comparisons

Despite much in the literature citing the difficulties of linking theory to practice and, in particular, the lack of standardized measures for attitudinal and behavioural change (Atree, 2006) some studies have been able to demonstrate that increased knowledge and skills impacts on care delivery of educational programmes. Brazil et al., (2006) argue that increasing confidence in Residential Aged Care staff to discuss issues around death and dying with the resident's family is a major predictor of the provision of quality care to residents at end of life. Education does make a difference to practice according to Kenny (2001). By increasing staff confidence and knowledge, staff were able to state that they felt more skilled at caring. In my research exploring the impact of the WDHB Palliative Care Education Programme, confidence was mentioned often by staff in the focus groups and it was linked to many sub themes in particular communication, the needs of the family/whānau and increased knowledge and understanding. Although there was no formal assessment of quality of care, improvements are likely after such an educational programme.

Froggatt (2000b) found a change in the approach to the care residents received from staff, who had undertaken Palliative Care Education. Feedback from the Residential Aged Care facility managers of these staff were that the care to their residents had improved. They felt this was due to the new knowledge being used with many residents not just those deemed to be dying and that staff felt better able to cope having conversations about death and dying if it was the resident's wish. Froggatt (2000a) also found that the education had heightened awareness of the needs of the families and friends and following participation in the Palliative Care education, staff were making time, providing support and involving the relatives more in the resident's care. This impact was very evident throughout all the transcripts in my research and is reflected in other international studies (Curry et al., 2009; Phillips et al., 2008).

Validation of existing knowledge, skills and practices was an important impact for staff who participated in the WDHB Palliative Care Education Programme. Other studies had similar

findings with this affirmation leading to an increased confidence of staff in their work ability (Froggat, 2000a). This increased confidence then empowered staff in their ability to assess and manage symptoms more effectively (Curry et al., 2009). There was also a perception that the education had reduced staff fears about caring for dying residents which led to less avoidance behaviour. In my research study, staff spoke of a change in behaviour by not avoiding relatives and dying residents following the education.

A lack of understanding of the principles of Palliative care means that residents are not having their Palliative Care needs met (McDonnell et al., 2009). Phillips et al., (2008) found that a greater understanding of Palliative Care concepts prompted changes in practices and this was evident across the transcripts in my research study with staff speaking about asking better questions, conducting fuller holistic assessments and having a raised awareness of the Palliative Care Approach particularly from staff of non-Western cultures.

Strengths and Limitations

The strengths of the research study looking at the impact of the WDHB Palliative Care Education Programme were that a good range of ethnicities were represented in the focus groups and that they comprised of a range of different Residential Aged Care settings. The focus groups worked well with staff speaking openly about their experiences. Limitations of the study were that focus groups were not held in every facility that participated in the WDHB Palliative Care Education Programme meaning generalizability is not assured. There was no control group, thus causality cannot be commented on. There was also a lack of consumer feedback; and we did not measure hard outcomes i.e. assess quality of care in any direct way.

Implications for practice

Any future education initiatives would be advised to be based on the individual needs of the Residential Aged Care facility, value the existing expertise and knowledge of the staff and take into consideration the diverse cultural and ethnic mix of both residents and staff. Engagement with the facility managers is vital to ensure that they are supportive of the Palliative Care Approach and have a clear understanding themselves of this approach and

how they see the new learning being embedded into their organisational culture. To make the learning more meaningful, educators could meet facility managers and staff prior to the session delivery to find out what the Palliative Care issues are for them and to bring along a case study to the session that they are dealing with currently.

Managers also need to value the acknowledgment of a resident's death by adopting rituals and practices at an organisational level that enable staff to manage successive losses.

With increasing number of residents having cognitive impairment, education content must ensure these residents and their families/whānau Palliative Care needs are being met.

Particular attention could be given to Rest Homes who are experiencing higher acuity levels in their residents and rising numbers of deaths. Rest Home staff need to not only feel supported and confident they have skills to provide quality Palliative Care for their residents and families/ whānau but that they have the insight to know when to refer on and that those teams will respond appropriately. Attention to adequate staffing levels to supply effective palliative care is important. Education cannot replace hands on staff.

Education alone is not sufficient to change attitudes and practices, clinical teams need to be aware of the education content, ideally be part of its delivery where possible and to then mentor and support the changes in practice.

Implications for future research

Finally, evaluation of any education intervention needs to be discussed from the outset. Those requesting the education need to be thinking of ways to measure its effectiveness and how it impacts on care outcomes. Ideally participants knowledge levels, behaviours and attitudes should be measured prior to and following the education delivery along with satisfaction surveys for residents and their families/whānau. Tools that measure hard outcomes can be employed such as Quality of life or symptom management indicators. Use of a control group would also be useful so comparisons can be made. Data around place of death and also acute hospital admissions from Residential Aged Care facilities need to be gathered.

Residential Aged Care staff including management need access to affordable evidence-based Palliative Care education, timely clinical support from both Specialist Palliative Care and

Gerontology teams and a commitment to work collaboratively with the resident and their family/ whānau to meet their individual needs regardless of their diagnosis and prognosis. Residential Aged Care staff need to be explicitly acknowledged for their expertise and skill, with many Residential Aged Care facilities caring for residents living well, with complex Palliative Care needs, until they die.

Hospice teams are well placed to support and encourage a shift in society's thinking that you do not have to have Hospice involvement to die well. Everyone is entitled to good Palliative Care regardless of their care setting and should therefore not be exclusive to the few that fit Hospice referral criteria.

In evaluating this educational programme with a qualitative study of the views and reflections of staff, much has been learned that will be useful in future educational programmes and an appreciation of the essential role RAC staff play in delivery of effective care, was understood.

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Appendix 1 – Ground rules

GROUND RULES

Phones silent/switched off

Good time keeping-

Start and finish on time -How long do I wait before I start if people are late

Confidentiality-

Personal stuff stays in the room but the learning is OK to share. Not using residents real names when sharing stories

Non-judgemental

One voice at a time

Respectful listening

Agree to disagree

Timeout

Appendix 2 – Supportive letters – Maori and Asian support

Appendix 3 – RAC Manager Letter

2012

Facility Manager
Residential Aged Care Facility

Dear,

Re: WDHB Palliative Care Education Programme 2011 – Research Study

I am pleased to announce that I have been granted ethics approval to conduct the research study that I mentioned to you during the delivery of the WDHB Palliative Care Education Programme.

The purpose of the research is to gather evidence of the impact of the learning for staff that have attended at least 4 of the 6 sessions. A list of those attendees from your facility is enclosed, and a maximum of 8 attendees is required. I attach an information sheet that details the study, with a copy for you, as Manager of the facility and another copy for any potential participants from the enclosed attendee list. I would be grateful if you could hand these out to interested staff.

The ethics committee have strict guidelines that I need to adhere to. In brief, I am not permitted to approach participants myself to ask them to volunteer for the study, I cannot conduct the focus group interviews. The focus group interview will therefore be conducted by my colleagues Sandra Sanderson who is a Senior Nurse and Educator at North Shore Hospice and Pauline Howell the Education Team administrator. A signed consent form from yourself and the group participants is required, prior to the focus group interview being conducted. I have given you a draft copy of the consent forms for your information.

In the first instance, I would like to come to your facility to discuss, in person, the focus group interview and consent process with those participants who would like to take part in the research study. Ideally this would occur the week before the focus group interview is scheduled to take place. To arrange dates for the focus group interview and for my initial visit, can I please ask you to contact Pauline Howell by email: paulineh@nshospice.org.nz or phone her direct number 485 3573, her working days are Tuesday, Thursday and Friday.

The focus group interview will be of 1 hour duration and held at your facility, as detailed in the information sheets. I would like to suggest that this take place at the same time slot as the education was delivered, (if this time is still the most convenient for you). The focus group interview will be recorded using a digital voice recorder so this session will need to be held in a closed room. Sandra and Pauline will bring a cake and fruit juice but would appreciate access to tea and coffee making facilities.

An important aspect of education is measuring its effectiveness, not just to inform the educators but to show its worth to the stakeholders, in this case the WDHB, yourselves & Hospice Boards. The impact of educational interventions on care outcomes, needs to be determined, however few empirical studies actually show how education affects practice and

there is a lack of standardised measures for attitudinal and behavioural change. My hope is that this research study will go some way to address this issue and provide the evidence we seek. This can only be done with your support and I would like to take this opportunity to thank you for considering my request.

I would appreciate you completing and returning the attached slip in order to give me an indication as to your facilities interest in taking part in this study.

I look forward to hearing from you.

Yours sincerely

Claire Hatherell
CNE Community

Re: WDHB Palliative Care Education Programme 2011 – Research Study

To: Pauline Howell, Hospice North Shore

Residential Aged Care Facility

Yes we are interested in taking part in the above study

Request contact by hospice administrator to arrange dates

No we are not interested in taking part in the above study

Appendix 4 – RAC Facility Manager Information sheet



School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
Email: p.huggard@auckland.ac.nz

Ref: 2011/312

Residential Aged Care Facility Manager Information Sheet

To: *(Name of Residential Aged Care Facility Manager)*

My name is Claire Hatherell. I am a staff member of North Shore Hospice and a student at the University of Auckland enrolled for a Masters Degree in Health Sciences. I am conducting this research for the purpose of my thesis entitled:

Exploring the impact of the Palliative Care Education Programme delivered by Hospice Educators for Residential Aged Care facilities in the Waitemata District Health Board (WDHB).

I am inviting your staff to voluntarily participate in my research and I would appreciate any assistance you can offer me.

Project Description

The aim of this project is to explore the impact on your staff who attended the WDHB Palliative Care Education Programme which was delivered by myself the Hospice Educator, at your Residential Aged Care Facility. The purpose of this education programme was to “influence their practice resulting in improved care outcomes for your residents with palliative care needs.” One way to measure this outcome involves asking your staff to share with an independent practitioner whether they have been able to apply the learning from this education programme, to their role at your Residential Aged Care facility. I would like to invite your staff therefore to take part in a focus-group interview, along with a maximum of 8 other colleagues from your facility. All of them will have attended between 4 and 6, of the 1 hour education sessions.

Project Procedures

The focus-group interview will take place at your facility during the same time slot as the education sessions were held and for the duration of one hour and mutually agreed by yourself as Facility Manager. Refreshments will be provided. Participation in the focus-group is voluntary. The interviews will be conducted by an independent practitioner, who has signed a confidentiality agreement and recorded using a digital voice recorder. A Co-facilitator who is another member of the WDHB Palliative Care Education Team and who has signed a confidentiality agreement may be present. Your staff can choose not to answer any specific questions. Your staff may choose to leave the focus group interview at any time however any information they have provided, cannot be withdrawn. If they state that they do not wish to remain present at the focus group, their Demographic Information Form will be returned to them. You as facility manager, have the option to withdraw your facility from the research study up until the commencement of the focus group interview. Following analysis

of the data gathered from the focus group interview, your staff will be invited to a 30 minute meeting. This will be voluntary and it will for the purpose of providing them with a summary report of the focus group interview.

Data storage/retention/destruction/future use

The digital voice recordings will be transcribed by the North Shore Hospice Palliative Care Development Team Administrator, who has signed a confidentiality agreement. Once transcribed, the digital voice recordings will be destroyed. During this process the digital voice recorders will be kept at North Shore Hospice, in a locked drawer in a locked office and will only be accessible to the North Shore Hospice Palliative Care Development Team Administrator. After transcription, only the de-identified transcripts will be available to the researcher. The de-identified transcripts will be stored electronically and password protected. The de-identified transcripts will only be accessible to the North Shore Hospice Palliative Care Development Team Administrator and the Hospice Educators all of whom have signed confidentiality agreements. The de-identified transcripts will be retained for 6 years then they will be destroyed.

Anonymity and Confidentiality

No material that could personally identify your staff will be used in any reports on this study. In the information that they provide, your staff will be identified by role and ethnicity only and the Residential Aged Care facility you work at will not be named or identified in any other way. Results from this study may be published. Confidentiality with respect to a participant's identity cannot be guaranteed due to the nature of the focus-group interviews however we will re-establish the ground rules that were used during the Palliative Care Education Programme sessions. These ground rules were as follows:

- Phones silent/ switched off
- Good time keeping, start and finish on time
- Confidentiality- Not using residents real names when sharing stories
- Non-judgemental
- One voice at a time
- Respectful listening
- Agree to disagree
- Timeout

Research Funding

I am employed by North Shore Hospice. I have received funding from Health Workforce New Zealand to undertake this Post Graduate Study.

Thank you very much for your time and help in making this study possible. If you have any queries or wish to know more please phone me at the number given below or write to me at:-

Claire Hatherell
C/- Department of General Practice & Primary Health Care
School of Population Health
Faculty of Medical Health Sciences
Morrin Road, Glen Innes
PO Box 92019
Auckland
Ph: 923 4500
chat@aucklanduni.ac.nz

My Supervisor is:

Professor Rod MacLeod
Department of General Practice and Primary Care
Faculty of Medical and Health Sciences
The University of Auckland
Private Bag 92019
Auckland
Tel. 09 373 7599 Ext 86082
rd.macleod@auckland.ac.nz

The Head of Department is:

Professor Bruce Arroll
Department of General Practice and Primary Care
The University of Auckland
Private Bag 92019
Auckland
Tel. 9236978
e-mail b.arroll@auckland.ac.nz

For any queries regarding ethical concerns please contact:-

The Chair
The University of Auckland Human Participants Ethics Committee
The University of Auckland Research Office-Office of the Vice Chancellor
Private Bag 92019
Auckland
Tel. 09 9237830

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON (DATE) FOR A PERIOD OF (NUMBER) YEARS. REFERENCE NUMBER (NUMBER).

Appendix 5 – Participant Information Sheet



School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
Email: p.huggard@auckland.ac.nz

Ref: 2011/312

Participant Information Sheet

To: Residential Aged Care Staff at (*Name of the Facility*)

My name is Claire Hatherell. I am a staff member of North Shore Hospice and a student at the University of Auckland enrolled for a Masters Degree in Health Sciences. I am conducting this research for the purpose of my thesis entitled: -

“Exploring the impact of the Palliative Care Education Programme delivered by Hospice Educators for Residential Aged Care facilities in the Waitemata District Health Board.”

I am inviting you to voluntarily participate in my research and I would appreciate any assistance you can offer me.

Project Description

The aim of this project is to explore the impact of the Palliative Care Education Programme you attended which was delivered by myself a Hospice Educator, at your Residential Aged Care Facility. The purpose of this education programme was to “influence your practice resulting in improved care outcomes for your residents with palliative care needs.” One way to measure this outcome involves asking you to share with an independent practitioner whether you have been able to apply the learning from this education programme, to your role at the RAC facility. I would like to invite you therefore to take part in a focus-group interview, along with a maximum of 8 other colleagues from your facility. All of you will have attended between 4 and 6, of the 1 hour education sessions.

Project Procedures

The focus-group interview will take place at your facility during the same time slot, as the education sessions were held and for the duration of one hour and mutually agreed by your Facility Manager. Refreshments will be provided. Participation in the focus-group is voluntary. The interviews will be conducted by an independent practitioner, who has signed a confidentiality agreement and they will be recorded using a digital voice recorder. A Co-facilitator who is another member of the WDHB Palliative Care Education Team and who has signed a confidentiality agreement will be present. You can choose not to answer any specific questions. You may choose to leave the focus group interview at any time however any information you have provided, cannot be withdrawn. If you state that you do not wish to remain present at the focus group, your Demographic Information Form will be returned to you. Your facility manager has the option to withdraw the facility from the research study, up until the commencement of the focus group interview. Following analysis of the data gathered from the focus group interview, you will be invited to a 30 minute meeting. This will be voluntary and it will be for the purpose of providing you with a summary report of the focus group interview.

Data storage/retention/destruction/future use

The digital voice recordings will be transcribed by the North Shore Hospice Palliative Care Development Team Administrator, who has signed a confidentiality agreement. Once transcribed, the digital voice recordings will be destroyed. During this process the digital voice recorders will be kept at North Shore Hospice, in a locked drawer in a locked office and will only be accessible to the North Shore Hospice Palliative Care Development Team Administrator.. After transcription, only the de-identified transcripts will be available to the researcher. The de-identified transcripts will be stored electronically and password protected. The de-identified transcripts will only be accessible to the North Shore Hospice Palliative Care Development Team Administrator and the Hospice Educators all of whom have signed confidentiality agreements. The de-identified transcripts will be retained for 6 years then they will be destroyed.

Anonymity and Confidentiality

No material that could personally identify you will be used in any reports on this study. In the information that you provide, you will be identified by role and ethnicity only and the Residential Aged Care facility you work at will not be named or identified in any other way. Results from this study may be published. Confidentiality with respect to a participant's identity cannot be guaranteed due to the nature of the focus-group interviews however we will re-establish the ground rules that were used during the Palliative Care Education Programme sessions. These ground rules were as follows:

- Phones silent/ switched off
- Good time keeping, start and finish on time
- Confidentiality- Not using residents real names when sharing stories
- Non-judgemental
- One voice at a time
- Respectful listening
- Agree to disagree
- Timeout

Research Funding

I am employed by North Shore Hospice. I have received funding from Health Workforce New Zealand to undertake this Post Graduate Study.

Thank you very much for your time and help in making this study possible. If you have any queries or wish to know more please phone me at the number given below or write to me at:-

Claire Hatherell
C/- Department of General Practice & Primary Health Care
School of Population Health
Faculty of Medical Health Sciences
Morrin Road, Glen Innes
PO Box 92019
Auckland
Ph: 923 4500
chat@aucklanduni.ac.nz

My Supervisor is: Professor Rod MacLeod
Department of General Practice and Primary Care
Faculty of Medical and Health Sciences
The University of Auckland
Private Bag 92019
Auckland
Tel. 09 373 7599 Ext 86082
rd.macleod@auckland.ac.nz

The Head of Department is:

Professor Bruce Arroll
Department of General Practice and Primary Care
The University of Auckland
Private Bag 92019
Auckland
Tel. 9236978
e-mail b.arroll@auckland.ac.nz

For any queries regarding ethical concerns please contact:-

The Chair
The University of Auckland Human Participants Ethics Committee
The University of Auckland Research Office-Office of the Vice Chancellor
Private Bag 92019
Auckland
Tel. 09 9237830

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Appendix 6 – Consent form for Facility Manager



Ref: 2011/312

School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
Email: p.huggard@auckland.ac.nz

Consent form for Facility Managers

This form will be held for a period of 6 years

Dear (Name of Facility Manager)

Project Title:

Exploring the impact of the Palliative Care Education Programme delivered by Hospice Educators for Residential Aged Care facilities in the Waitemata District Health Board.

Researcher:

Claire Hatherell,
Community Liaison & Education Facilitator
North Shore Hospice Trust,
7 Shea Terrace,
Takapuna 0622
Auckland
Master of Health Sciences Student,
School of Population Health,
University of Auckland

I have read the Facility Manager Information Sheet and I have understood the nature of the research and why staff at (Name of Facility) have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to my staff taking part in this research
- I understand that my staff will be recorded however they may choose not to answer any questions and they may choose to leave the interview at any time.
- I understand that withdrawal of information that my staff have provided, is not possible from the focus group interview.
- I understand that I have the option to withdraw involvement of my facility from the research at any time up until the commencement of the focus group interview

- I understand that there will be a co-facilitator present at the focus group interview and that they have signed a confidentiality agreement
- I understand that the results of the research might be published
- I wish/do not wish to receive the summary of the findings
- I understand that the Administrator from the North Shore Hospice Palliative Care Development team, who has signed a confidentiality agreement, will transcribe the digital voice recordings.
- I understand that data will be kept securely for 6 years, after which it will be destroyed
- The names of those staff agreeing or not agreeing to participate in the study will not be given to me.
- I guarantee that, in no way at all, will staff members agreement or non-agreement to participate affect their employment with this organisation

Name

Title

Signature

Date

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ONfor (3) years, Reference Number...../.....

Appendix 7 – Consent form for participants



Ref: 2011/312

School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
Email: p.huggard@auckland.ac.nz

Consent form for participants

This form will be held for a period of 6 years

Dear Participant at (Name of the Residential Aged Care Facility)

Project Title:

Exploring the impact of the Palliative Care Education Programme delivered by Hospice Educators for Residential Aged Care facilities in the Waitemata District Health Board.

Researcher:

Claire Hatherell,
Community Liaison and Education Facilitator
North Shore Hospice Trust
7 Shea Terrace,
Takapuna 0622
Auckland
Master of Health Sciences Student,
School of Population Health,
University of Auckland

I have read the Participation Information Sheet; have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to take part in this research
- I understand that I will be recorded however I may choose not to answer any questions and I may choose to leave the interview at any time.
- I understand that withdrawal of information that I have provided, is not possible from the focus group interview.
- I understand that the facility manager has the option to withdraw involvement of the facility from the research at any time up until the commencement of the focus group interview

- I understand that participation or non-participation will not affect my employment here at (name of Residential Aged Care facility)
- I understand that there will be a co-facilitator present at the focus group interview and that they have signed a confidentiality agreement
- I understand no material that could personally identify me will be used in any report of this study
- I understand I will be identified by role and ethnicity only and that the Residential Aged Care facility will not be identified.
- I agree to abide by the ground rules that were used during the Palliative Care Education Programme sessions i.e. Phones silent/ switched off, Good time keeping, start and finish on time, Confidentiality- Not using residents real names when sharing stories, Non-judgemental, One voice at a time, Respectful listening, Agree to disagree, Timeout.
- I agree to not disclose anything discussed in the focus-group to any other person.
- I wish/do not wish to receive the summary of the findings
- I understand that the results of the research might be published
- I understand that the North Shore Hospice Palliative Care Development Team Administrator, who has signed a confidentiality agreement, will transcribe the digital voice recordings.
- I understand that data will be kept for 6 years, after which it will be destroyed

Name

Signature

Date

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ONfor (3) years, Reference Number...../.....

Appendix 8 – Interview Guide



Ref: 2011/312

School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
Email: p.huggard@auckland.ac.nz

Interview Guide

Project Title:

Exploring the impact of the Palliative Care Education Programme delivered by Hospice Educators for Residential Aged Care facilities in the Waitemata District Health Board.

Researcher:

Claire Hatherell,
Community Liaison & Education Facilitator
North Shore Hospice Trust,
7 Shea Terrace,
Takapuna 0622
Auckland
Master of Health Sciences Student,
School of Population Health,
University of Auckland

Project Aims:

To explore the impact of a Palliative Care Education programme. To search for evidence of application of learning to the practice setting and improved care outcomes for residents with palliative care needs.

Focus-group questions:

1. How has the education affected you personally?
2. How has the education affected your role at the Residential Aged Care facility?
3. How has the education impacted on how you care for the residents with Palliative Care needs in your facility?

Appendix 9 – Co-Researcher Confidentiality Agreement



Ref: 2011/312

School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Co-researcher Confidentiality Agreement

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
Email: p.huggard@auckland.ac.nz

Project Title:

Exploring the impact of the Palliative Care Education Programme delivered by Hospice Educators for Residential Aged Care facilities in the Waitemata District Health Board.

Researchers:

Professor Rod MacLeod, Department of General Practice and Primary Care, Faculty of Medical and Health Sciences, The University of Auckland, Private Bag 92019, Auckland

Claire Hatherell, Community Liaison & Education Facilitator, North Shore Hospice Trust, 7 Shea Terrace, Takapuna 0622, Auckland. Master of Health Sciences Student, School of Population Health, University of Auckland.

I (full name).....

have been engaged by Claire Hatherell to assist with coding consistency checks for the research study named above. All information gained from assisting in this task will be treated as confidential and I will not identify any person involved in focus groups. No information about the content of these groups will be passed on to a third party.

Signed:

Date:/...../.....

Witness full name:

Witness job and address:

Witness signature:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ONfor (3) years, Reference Number...../.....

Appendix 10 – Facilitator Confidentiality Agreement



Ref: 2011/312

Facilitator Confidentiality Agreement

School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
Email: p.huggard@auckland.ac.nz

Project Title:

Exploring the impact of the Palliative Care Education Programme delivered by Hospice Educators for Residential Aged Care facilities in the Waitemata District Health Board.

Researchers:

Professor Rod MacLeod, Department of General Practice and Primary Care, Faculty of Medical and Health Sciences, The University of Auckland, Private Bag 92019, Auckland

Claire Hatherell, Community Liaison & Education Facilitator, North Shore Hospice Trust, 7 Shea Terrace, Takapuna 0622, Auckland. Master of Health Sciences Student, School of Population Health, University of Auckland.

I (full name).....

have been engaged by Claire Hatherell to conduct focus group interviews for the research study named above.

I declare that I will not discuss or divulge any information that I may hear on these recordings and in particular I will not identify any of the persons or organizations making the recordings or referred to in the recordings.

All focus group data, including digital voice recordings, will be returned to the researcher for storage. I will not retain copies on paper, electronic or any other form of storage.

Signed:

Date:/...../.....

Witness full name:

Witness job and address:

Witness signature:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ONfor (3) years, Reference Number...../.....

Appendix 11 – Co-Facilitator Confidentiality Agreement

Ref: 2011/312

School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
Email: p.huggard@auckland.ac.nz

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I (full name).....

have been engaged by Claire Hatherell to co-facilitate focus group interviews for the research study named above. All information gained from co-facilitation will be treated as confidential and I will not identify any person involved in focus groups. No information about the content of these groups will be passed on to a third party.

Signed:

Date:/...../.....

Witness full name:

Witness job and address:

Witness signature:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ONfor (3) years, Reference Number...../.....

Appendix 12 – Transcribers Confidentiality Agreement



School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
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I (full name).....

have been engaged by Claire Hatherell to transcribe audio recordings for the research study named above.

I declare that I will not discuss or divulge any information that I may hear on these recordings and in particular I will not identify any of the persons or organizations making the recordings or referred to in the recordings.

While I am working on them, I will keep digital voice recordings in locked storage and electronic copies under password protection. This password will only be known to myself and the researcher. All focus group data, including digital voice recordings, will be returned to the researcher for storage. I will not retain copies on paper, electronic or any other form of storage.

Signed:

Date:/...../.....

Witness full name:

Witness job and address:

Witness signature:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ONfor (3) years, Reference Number...../.....

Appendix 13 – Interview Guide – Detailed

Interview Guide

Project Title:

Exploring the impact of the Palliative Care Education Programme delivered by Hospice Educators for Residential Aged Care facilities in the Waitemata District Health Board.

Project Aims:

To explore the impact of a Palliative Care Education programme. To search for evidence of application of learning to the practice setting and improved care outcomes for residents with palliative care needs.

Focus-group questions:

1. How has the education affected you personally?
2. How has the education affected your role at the RAC facility?
3. How has the education impacted on how you care for the residents with Palliative Care needs in your facility?

Before the interview

Check equipment is working-Dictaphone has charged batteries-take spares
Pre-test and know your questions, be familiar with the aims of the study/requirements of the interview
Remind Facility Managers one week before of the focus-group interviews
Ensure a suitable room is made available, preferably away from the residents to maintain privacy & confidentiality
Schedule sufficient time for the interview
Arrive at the RAC on time
Explain to potential participants the purpose and conditions of the interview, including confidentiality and audio-taping.
Take ground rules from the Palliative Care Education Project
Ensure the consent forms have been completed
Take refreshments

At the interview

Set out the refreshments
Position furniture conducive to the interview format
Introduce the interview and remind participants of the aims of the study and the purpose of the focus-group.
Collect the consent forms before commencement of audio-taping, review rights of participants, use of results

At the interview (Cont'd)

Remind participants that they can end the interview at any time

Take paper in case the audio tape fails

Position the Dictaphone close to participants and check it is recording immediately

Develop a rapport with the participants- remain relaxed and communicate clearly in the participant's terms

Listen actively, do not interrupt or finish sentences

Stay neutral

Facilitate the discussions using the ground rules as a guide to ensure respectful listening, one voice at a time

Ask the 3 study questions one at a time

Probe and persist to obtain politely the detail you need. Keep participants focused on answering your balanced questions

Once everyone has had an opportunity to answer the 3 questions, offer the group an opportunity to add anything else that they feel is important to them with regards the Education Programme

Keep to time, 1 hour maximum

End the interview positively thanking participants for their valuable contributions

End of the interview

Summarise the main points to check understanding

Thank the RAC facility manager for their support

Ensure they have your contact details

Immediately after the interview

Test the audiotape and write up your notes

Return the audio tape to North Shore Hospice and ensure it is locked in Claire's drawer in the Education Office

Appendix 14 – Demographic Form



Ref: 2011/312

School of Population Health
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland
New Zealand,

Demographic Form

Morrin Road, Glen Innes
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 84500
Facsimile: 64 9 373 7624
Email: p.huggard@auckland.ac.nz

Project Title:

Exploring the impact of the Palliative Care Education Programme delivered by Hospice Educators for Residential Aged Care facilities in the Waitemata District Health Board.

Researcher:

Claire Hatherell,
Community Liaison & Education Facilitator
North Shore Hospice Trust,
7 Shea Terrace,
Takapuna 0622
Auckland
Master of Health Sciences Student,
School of Population Health,
University of Auckland

Please complete the following:-

Age Group 20-29; 30-39; 40-49; 50-59; 60-69

(Please Circle Appropriate Age Group)

Ethnicity

New Zealand European/Pakeha European

Maori Pacific Island

Asian

Other **Please state:** _____

Gender

Male

Female

Job title and grade _____

Employer _____

Are you part-time or full time? Part-Time (please state average number of hours

worked per week)

Full-Time

Professional qualifications _____

Length of time at this Residential Aged Care facility _____

Prior to this, length of time in similar jobs _____

Extent of palliative care training

**Appendix 15 – Guidelines for WDHB Palliative Care Education Programme for Facility
Manager**

Guidelines for WDHB Palliative Care Education Programme

Purpose

WDHB and the Hospices in the Waitemata region recognise the increasing number of residents with complex palliative care needs within your care sector resulting in funding being made available to develop a programme of meaningful, evidence-based palliative care education for the residential aged care facilities within the Waitemata District Health Board (WDHB) region.

This ongoing education programme will enable us to continue to develop existing relationships and foster a greater understanding of each other's roles.

Aim

The aim of this education programme is to raise awareness and increase confidence of palliative care issues for residential aged care staff. We envisage this will be achieved through building on their existing knowledge and skills.

Education Programme

We offer six, 1-hour sessions, to be delivered on site, free of charge at a mutually convenient time. These sessions will be delivered to staff of all disciplines, e.g. RN's, HCA's, physiotherapists, housekeeping/domestic staff, chaplain etc. by a Hospice Palliative Care Educator with support from the Hospice multi-disciplinary team, over a six week period. The equipment and resources required for each session will be provided by the Hospice Palliative Care Educator.

We would appreciate your support and assistance to enable as many of your staff as possible to attend. This would involve timely advertising for which we would provide assistance. In our experience delivering palliative care education, the content can trigger emotional responses for staff. This can be valuable learning and we will provide a mechanism for support.

In order to gauge the effectiveness of the programme, we will hold a focus group with up to eight of your staff attending the education approximately six weeks after the last session date. The focus group is voluntary, and we are hoping for staff from many roles to include RN's, HCA's, carers, administrative and hospitality staff to attend. These focus groups will be audio recorded and confidential. Refreshments will be provided and a timetable of no more than one hour will be strictly adhered to.

Continuing evaluation of the education programme will be undertaken following delivery of each session and this process will be confidential. Evaluation of the entire programme will be reported to the WDHB with each facility remaining confidential.

We envisage participation in this programme will nurture resilience in your staff and increase their capacity to cope in the often challenging environment of residential aged care. We also anticipate this will enhance your profile within the community as a quality palliative care provider.

Contact details:

Claire Hatherell, Clinical Nurse Specialist Community Education

North Shore Hospice, 7 Shea Terrace, Takapuna, 0740.

Ph: 09 486-1688 Ext: 722 DDI: 486 3522 E-Mail: claireh@nshospice.org.nz

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