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**THE STATUS
OF A PUBLIC HEALTH APPROACH TO PALLIATIVE CARE
AT NEW ZEALAND HOSPICES**

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**A thesis submitted in fulfilment of the requirements
for the degree of
Master of Health Science**

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ABSTRACT

Background: There is growing international support for a public health approach to palliative care; however the status of the movement in the local New Zealand context is unknown.

Aim: To explore the uptake, nature and understandings of a public health approach to palliative care by hospices in New Zealand.

Methods: A mixed method study using a convergent parallel design was conducted. In phase 1 quantitative data were collected using an online survey of hospice leaders, and in phase 2 qualitative data were generated from semi-structured telephone interviews with a sub-sample of phase 1 participants. Data from the survey were analysed using appropriate statistical techniques. Transcripts of the telephone interviews were analysed using thematic analysis. The findings from each phase were then triangulated to check for congruency.

Sample: Fifteen leaders (12 chief executive officers, and three senior managers) at New Zealand hospices participated in the online survey, representing a response rate of 54%. Ten of these participants took part in a semi-structured telephone interview.

Results: Analysis of the quantitative results confirmed that a public health approach to palliative care was a current priority at 60% of New Zealand hospices. However, both phases of the study demonstrated that community engagement, one of the chief outworkings of a public health approach to palliative care, was incompletely understood and practiced. Furthermore, the qualitative results showed that, while this approach is supported, there are significant barriers to implementation, including paternalism, resource constraints, adequate evaluation, and incomplete understanding of key concepts such as social networking and community engagement.

Conclusion: This study is the first to explore the extent to which a public health approach to palliative care is supported by hospices in New Zealand. The unique new findings have important implications for practice. If the model is to be implemented to maximum benefit, further conceptual clarity of the key tenets is needed. In addition, addressing the barriers to implementation identified by this study will need to be prioritised by hospice leadership.

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A copy of these manuscripts may be found as appendix 8 and 9 respectively.

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GLOSSARY OF ABBREVIATIONS

| | |
|--------|---|
| PHAPC | Public health approach to palliative care |
| WHO | World Health Organisation |
| PHPCI | Public Health and Palliative Care International |
| PHPCIA | Public Health and Palliative Care International Association |
| NGO | Non-government organisations |
| CBO | Community-based organisations |
| EOL | End of life |

CHAPTER ONE: INTRODUCTION TO THE STUDY

1.1 Introduction

This thesis is concerned with exploring a public health approach to palliative care (PHAPC) within the New Zealand context. Although the approach is well understood and supported in countries like the UK, it is relatively new to New Zealand. If adopted by palliative care services it would represent a significant shift in the way hospices provide care. It is a potential “re-fashioning” as Rosenberg, Mills and Rumbold (2016, p.2), prominent members of the palliative care community put it, in a recent editorial in the journal *Progress in Palliative Care*. This shift involves an intentional moving away from a professional, service driven approach towards working in partnerships with communities.

This first chapter will provide the background for the thesis. It will consider the definition and origin of PHAPC. It will also give an overview of the international and local uptake of the approach. Finally, the researcher’s personal perspectives and the rationale for the proposed study question will be outlined.

1.2 Definitions and origins

In order to gain a good understanding of a PHAPC, it is necessary first to consider the separate disciplines of *palliative care* and *public health*.

1.2.1 Palliative care

A widely used definition of palliative care is that adopted by the World Health Organisation (WHO), which states:

palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (2002).

However, many countries have their own local definitions. The New Zealand Palliative Care Glossary (Ministry of Health, 2015) defines palliative care as follows:

Palliative care is care for people of all ages with a life-limiting or life-threatening condition which aims to:

- optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs

- support the individual's family, whānau, and other caregivers where needed, through the illness and after death.

As these two rather broad and varied definitions demonstrate, there is no single, clear global definition of palliative care. There are elements of congruence, for example in the recipients being those with life-limiting conditions, the importance of quality of life, and the holistic approach to care. Still, there are scholars who contend that the boundaries of palliative care remain poorly defined (Clark, 2016).

The rise of the modern hospice movement occurred in the 60's and has been credited largely to the work of Dame Cecily Saunders (Twycross, 2008). In the early days, palliative care was predominantly for cancer patients and carried out by hospices. Over time it has shifted to encompassing care for those with all manner of chronic conditions and the drive is to have a health systems approach towards the delivery of care (Dzinga & Higginson, 2015).

1.2.2 Public health

Similarly to palliative care, many definitions of public health exist. One of the older, yet enduring definitions is that of Winslow (as cited in Baggot, 2000, pp. 1), which states

Public health is the science and art of preventing disease, prolonging life and promoting physical health and efficiency through organised community efforts for sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, the organisation of medical and nursing service for the early diagnosis and preventive treatment of disease, and the development of social machinery which will ensure to every individual in the community a standard of living adequate for the maintenance of health.

It may also be put in simpler terms, as being concerned with health issues from a population perspective (Baggot, 2000; Dzinga & Higginson, 2015).

The discipline of public health has experienced significant adaptations over time following changes in the causes of morbidity and mortality. In the 18th and 19th century the focus was on sanitation to prevent communicable diseases, while the 20th and indeed the beginning of the 21st century the focus has certainly been more geared towards addressing non-communicable diseases (Dzinga & Higginson, 2015).

One pivotal moment for public health took place in 1986 when the WHO endorsed the Ottawa Charter (WHO, 1986). The document framed a novel model of public health called *health promotion or the new public health* (Stephens, 2008). This model recognised the important influence of social, physical and

environmental determinants on health (Rosenberg, 2012). Of particular importance, the charter recognised the vital contribution that communities themselves can make in ensuring services provided are appropriate and sustainable. This participatory notion is one of the distinguishing features of health promotion (Kellehear & Sallnow, 2012). The Ottawa Charter is built on the values of prevention, harm reduction, early intervention, and sustainability, and has five central goals (Rosenberg, 2012). These are:

- i. Building healthy public policy
- ii. Creating supportive environments
- iii. Strengthening community action
- iv. Developing personal skills
- v. Re-orienting health services

The charter has since been criticised by post-colonialists for the dominant western influence in its development and content; however it certainly has been one of the most influential documents in terms of raising the profile of community involvement in health and the recognition of broader determinants of health (McPhail-Bell, Fredericks & Brough, 2013).

1.2.3 A public health approach to palliative care

Dzinga and Higginson (2015) imply that the first reference to palliative care being identified with public health, was in a paper by Wilkes published in The Lancet in 1984 (Wilkes, 1984). Others relate the first real linking of palliative care to public health to the WHO, and in particular to the then Chief of Cancer, Jan Stjernsward (Clark, 2016). Either way, palliative care is now commonly referred to as a public health concern, and it is often framed in the language of the WHO's public health model which aims to integrate palliative care into all levels of society. This strategy identifies policy, drug availability as key elements followed by education and implementation (Stjernsward, Foley & Ferris, 2007).

The linking of palliative care to that specific aspect of public health that this study is primarily concerned with, namely health promotion, is widely attributed to sociologist Allan Kellehear. In his first book on the topic, 'Health Promoting Palliative Care' he outlined how the principles of palliative care might be compatible with the principles of health promotion as outlined in the Ottawa Charter, and indeed how they might benefit each other. He built a case for a public health model of palliative care that incorporated principles from both disciplines (Kellehear, 1999a). A newer book, 'Compassionate Cities: Public health and end of life care' is an extension of Kellehears' thinking on a PHAPC (Kellehear, 2005). These ideas are now well known in Australia and the UK in particular, and have become a part of palliative care language and strategy, as will be discussed in the next section.

Given the complexities of the separate definitions of palliative care and public health, actually defining a PHAPC is not an easy task. Nonetheless, a PHAPC necessarily adopts the tenets of both palliative care and health promotion. It takes the principles of health promotion and applies them to addressing the morbidities and mortalities associated with death, dying and loss (Public Health and Palliative Care International, 2015). According to the Public Health and Palliative Care International Association (PHPCIA) (2015),

A public health approach to palliative care is a health promotion approach to end of life care, one that views the community as an equal partner in the long and complex task of providing quality health care at the end of life. Just as health, according to WHO, is ‘everyone’s responsibility’ so too is death, dying, loss and care.

The importance of social action is also recognised in Cohen and Deliens’ (2012) description of public health at the end of life.

In terms of *what actions* a PHAPC needs to include, Kellehear articulated the core concerns of a health promoting palliative care as including ALL of the following (Kellehear, 1999a):

- i. Health education
- ii. Death education
- iii. Social supports
- iv. Interpersonal reorientation
- v. Environmental reorientation and policy development

In terms of *how* a PHAPC might achieve these actions, the PHPCIA recognises six key *methods* that are important in outworking this approach:

- i. Participatory relations
- ii. Community development
- iii. Partnerships
- iv. Education
- v. Population health approach
- vi. An ecological settings emphasis

The diagram on the following page assists in tracking the development of a PHAPC, and summarises some of the points discussed above.

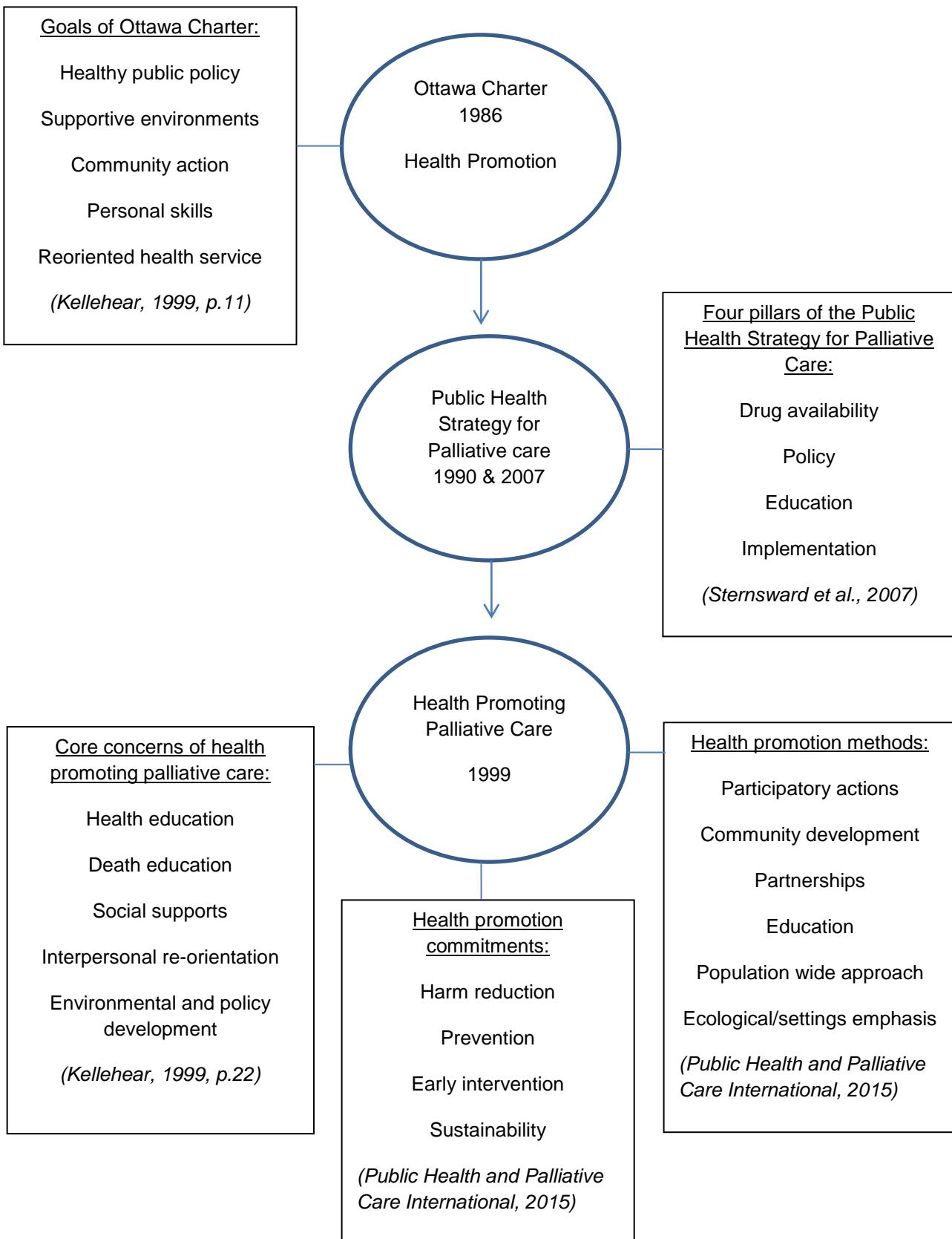


Figure 1: The development of public health approaches to palliative care (sources acknowledged)

1.3 International context

Aspects of a PHAPC have been in evidence for some time in developing countries. Perhaps one of the better known examples of this is the community development model, called the Neighbourhood Networks in Palliative Care (NNPC), in Kerala, India which was established in the late 1990's. This model was endorsed by the WHO in 2010 when it was designated as a 'WHO Collaborating Centre in Community Participation in Palliative and Long Term Care' (Sallnow, Khan & Uddin, 2011). The community in Kerala mobilised to provide holistic palliative care to its own citizens (Kumar, 2012). Volunteerism is a core element of the model, which has been successfully translated into other developing countries, such as Sri Lanka, Thailand and Indonesia (Zaman, 2015).

Although not explicitly acknowledging an intentional health promoting approach, community development approaches have been operating in South Africa over the last two decades. To meet the needs created by the HIV/AIDS pandemic, many non-government organisations (NGO's) and community-based organisations (CBO's) have stepped up to facilitate a range of medical and social support often provided by local communities for local communities (Conway, 2008). One example of this is the KwaZulu Natal HIV/AIDS outreach programme in Durban (Clemens et al., 2007). Staying in South Africa, most hospices use the Integrated Community Based Home Care model which was established in the nineties (Downing, Gwyther & Mwangi-Powell, 2012). This model provides professional support to the ill person and their carers, and builds capacity in communities (Downing et al., 2012).

In the UK, a PHAPC has gained significant traction through the compassionate community movement, which is at least seven years old (Barry & Patel, 2013). This approach exemplifies health promoting palliative care, and is unambiguously based on the work of Allan Kellehear. A recent scoping survey found a broad range of activities being carried out under this banner across England (Barry & Patel, 2013). The Dying Matters Coalition, led by the National Council for Palliative Care, was established in 2009, and has played an influential role in encouraging the compassionate community movement across all sectors of society and not only within palliative care services (Barry & Patel, 2013). In May 2015 the fourth PHPCI Conference was held in Bristol, and a number of established examples of implementing a PHAPC in the UK were showcased (PHPCI, 2015). In Scotland, where health promoting activities related to death and dying have been in existence since 2007 (Haraldsdottir, Murray & Clark, 2010), a public health focus on palliative care has been endorsed recently by the government in the Strategic Framework for Action on Palliative and End of Life Care (Clark, 2015b).

Closer to home in Australia, arguably the home of a PHAPC, the approach is relatively well accepted and elements thereof are even upheld in strategic policy documents, as detailed by Rosenberg and colleagues. (Rosenberg, Horsfall, Leonard, & Noonan, 2015). The ongoing work of Allan Kellehear and others, as well as the establishment of the palliative care unit within the School of Public Health at the University of LaTrobe University, are said to have contributed largely towards this achievement (Rumbold, 2012). However,

Rumbold, a well-known proponent of this approach, especially in bereavement work, says that more advocacy is needed to create a wider acceptance of public health approaches within palliative care circles (Rumbold, 2012). An increasing amount of influential research on PHAPC practice has been generated from within Australia, for example the work of on social capital (Horsfall, Noonan & Leonard, 2012) and the importance of identifying social networks (Rosenberg et al., 2015).

1.4 Local context

The bi-annual Hospice New Zealand conference in 2012 adopted the theme 'Community, Choice and Collaboration'. This conference featured keynote speakers who support a PHAPC, such as Bruce Rumbold, Heather Richardson and Joachim Cohen, all of whom actively advocated and referenced this approach (Hospice New Zealand, 2012). The existence of other such influential dialogue is unknown, as is the impact thereof on practice in New Zealand.

1.5 Personal perspective

I recently undertook a post-graduate diploma in public health, and as a palliative care nurse I was often questioned by my peers on the relevance of this course of study because to some the two disciplines seemed so incongruent. Although I inherently understood that there was benefit considering palliative care needs from a population perspective, I found myself struggling to articulate the connection between the two disciplines beyond that benefit. And always there was this question – *surely it's too late for health promotion in end-of-life care?* It is my opinion that health is still viewed by many as the absence of disease, despite the broader definitions of well-being put forward by the WHO in 1981 in their *Global Strategy for Health for All* by the Year 2000, and later in 1986 in the Ottawa Charter (WHO, 1986). For those who hold the older notion of health, it is difficult to consider that dying and health may not be mutually exclusive.

As I read more widely I came across the notion of a health promoting palliative care, which articulately applied the principles of health promotion to the features of death, dying and bereavement. I began to read the literature around the PHAPC and became intrigued by the complexities and possibilities of this approach. This philosophy made the link to public health more meaningful than simply taking a population perspective on palliative care. It finally made sense to me and certainly helped me finish my studies in public health, giving me the confidence I needed that my focus on the interface between the two disciplines was relevant and important.

However, although I felt more certain of the alignment between palliative care and public health, I retained a sense that my public health classmates, and even my lecturers, had quite different ideas of what a PHAPC actually entailed when compared with the social model Kellehear and others were advocating. The former appeared to be thinking of outcomes determined by health service interventions, whereas Kellehear was

talking more about grassroots ownership of health outcomes. In addition, I found that many of my palliative care colleagues did not even know about a PHAPC, despite a number of them having heard the rhetoric at the HNZ conference in 2012. Indeed, they experienced the same struggle that I had initially, to find the link between palliative care and public health.

Therefore, from a personal standpoint, undertaking this thesis not only gave me some first-hand research experience, but afforded me the opportunity to explore how well the concept of a PHAPC is understood and what level of support there is for the movement within the palliative care sector in New Zealand, specifically in hospices. I was particularly interested in investigating if indeed there are different schools of thought around what a PHAPC actually means, and as a first step, I hoped the literature review would shed some light on this.

1.6 Rationale for the study

The following reasons collectively describe the impetus for this thesis:

Firstly, a PHAPC is an important movement. Support for a PHAPC is growing internationally and the body of literature around it is increasing steadily. Examples of the approach exist in a number of countries, as has been demonstrated, and a designated international association (the PHCIA) was established in 2015 to provide direction and support for the movement.

Secondly the approach means change for palliative care services. It will require adjustments in strategic thinking and planning, from the current paradigm of service provision towards a more community engagement type approach.

Thirdly, the uptake of and support for a PHAPC in New Zealand is not known. In light of some of the conceptual challenges I encountered in myself and others, I also wondered how well the approach is understood within the palliative care sector locally.

Therefore, this study aims to explore the uptake, nature and understandings of a PHAPC within hospices in New Zealand.

CHAPTER TWO: INTEGRATIVE LITERATURE REVIEW

2.1 Introduction

This thesis explores the uptake, nature and understandings of a public health approach to palliative care (PHAPC) by hospices in New Zealand. The current chapter details the integrative literature review which informed this study, and which was primarily concerned with perceptions of a PHAPC. In particular there were three conceptual challenges that motivated the focus of the review.

The first and most important challenge is related to philosophical frameworks. Indeed, an initial reading of the literature, indicated to me that there appeared to be different schools of thought around a PHAPC. Recently in the editorial for a special edition of articles on community engagement in the journal *Progress in Palliative Care*, Rosenberg et al. (2016) acknowledged the, “breadth and ambiguity of public health frameworks” (p. 1). Another well-known scholar and author, David Clark (2015a), also highlighted this lack of clarity in one of his blog posts related to the European Association of Palliative Care Congress in 2015. He discussed how two conference speakers in particular seemed to render quite different images of public health as it relates to end-of-life care; the one being community focussed and the other being rather more health systems oriented.

Secondly, to add to the confusion, there exists a plethora of terms that are closely associated or synonymous with a PHAPC (Sallnow & Paul, 2014). These include actions (often described using the words *activities, process or methods*) and ideas (often described using the words *philosophy, framework, concept, model or approach*):

- Health promoting palliative care (Kellehear, 1999a) - idea
- Community development (Conway, 2008) - idea
- Community engagement (Sallnow & Paul, 2014) – action
- Compassionate communities (Barry & Patel, 2013) - idea
- Compassionate cities (Kellehear, 2005) - idea
- Social network approaches (Horsfall et al., 2012, Abel et al., 2013) - action
- Social capital (Horsfall et al., 2012) – idea

The third challenge is that there is a lack of understanding around some of the key concepts linked to a PHAPC (Barry & Patel, 2013; Rosenberg, 2012). For example, health promotion is often seen as merely health education, or simply work in the community, or yet another layer of service led by health professionals (Kellehear & Sallnow, 2012). Similarly, community engagement, a key method underpinning public health approaches, is often poorly or incompletely understood by end-of-life services (Sallnow & Paul, 2014).

Given these challenges, this literature review aimed to unpack and explore how a PHAPC is perceived by those authors claiming to support it. The review followed the framework put forward by Whittemore and Knafl (2005) for rigorous integrative literature reviews. This type of review was selected because it allows for the inclusion of qualitative and quantitative data for collection and analysis. The recommended stages of the framework form the outline of this chapter.

2.2 Problem identification stage

It is necessary to clearly define the purpose of any literature review, as this clarity helps guide all other stages of the process (Whittemore & Knafl, 2005). This is especially true considering the diverse methodologies and variables an integrative review is likely to unearth.

Since a public health approach is a relatively new model for palliative care, *the purpose of this review was to identify studies that explicitly claimed to use a PHAPC*. Of particular interest was how the authors understood the model by looking at the words and concepts they associated a PHAPC. This is in line with the overall research question (uptake, nature and understandings of a PHAPC).

2.3 Literature search stage

The search was carried out by CD with the help of a specialist librarian at Auckland University. The databases Cinhal, Medline and Psychinfo were searched using a combination of the search terms tabulated below. The search was limited to journal articles published between 2005 and 2015, and written in English.

Table 2.1: Search Terms

| Search terms | | |
|--------------|-----------------|--|
| | Core terms | Related terms |
| 1. | Palliative care | Hospice, terminal care, end-of-life care |
| 2. | Public health | Health promot*, promoting health Community engag*, community develop*, compassionate communities, compassionate cities Social capital, social network* |

Journal articles identified were then assessed for inclusion against the pre-determined inclusion and exclusion criteria depicted in Table 2.2.

Table 2.2: Inclusion and exclusion criteria

| Inclusion Criteria | Exclusion Criteria |
|---|--|
| Empirical research including evaluation studies | Opinion pieces and literature reviews |
| Conducted between 2005 and 2015 | Studies published before 2005 or after 2015 |
| Papers written in English | Papers written in any other language |
| Studies related to palliative care | Studies not related to palliative care |
| Papers that <i>explicitly</i> acknowledge their study as sitting within the framework of a public health or health promoting approach to palliative care, and use the exact search terms to describe this orientation | Papers that do not explicitly acknowledge their study as sitting within the framework of a public health or health promoting approach to palliative care |

The initial searches across all 3 databases yielded 1263 results. These were further refined by scanning the titles. Those that did not meet the criteria were rejected and 91 remained. After removing 26 duplicates, the remaining 65 articles were again refined by reading the abstracts. 28 were found to be non-empirical studies. Thirty-seven articles remained; these were again refined by searching the text for explicit acknowledgement of public health or health promotion. Nineteen articles did not meet these criteria and were excluded. At the end of the process 18 remained having met the inclusion criteria and were identified for inclusion in the data evaluation stage. Details of the selection process are outlined in the Preferred Reporting Items for Systematic Reviews and Meta- Analyses (PRISMA) chart (Moher, Liberati, Tetzlaff & Altman, 2009) at Figure 2.1. A brief summary of each study can be found in the data extraction table at Table 2.3).

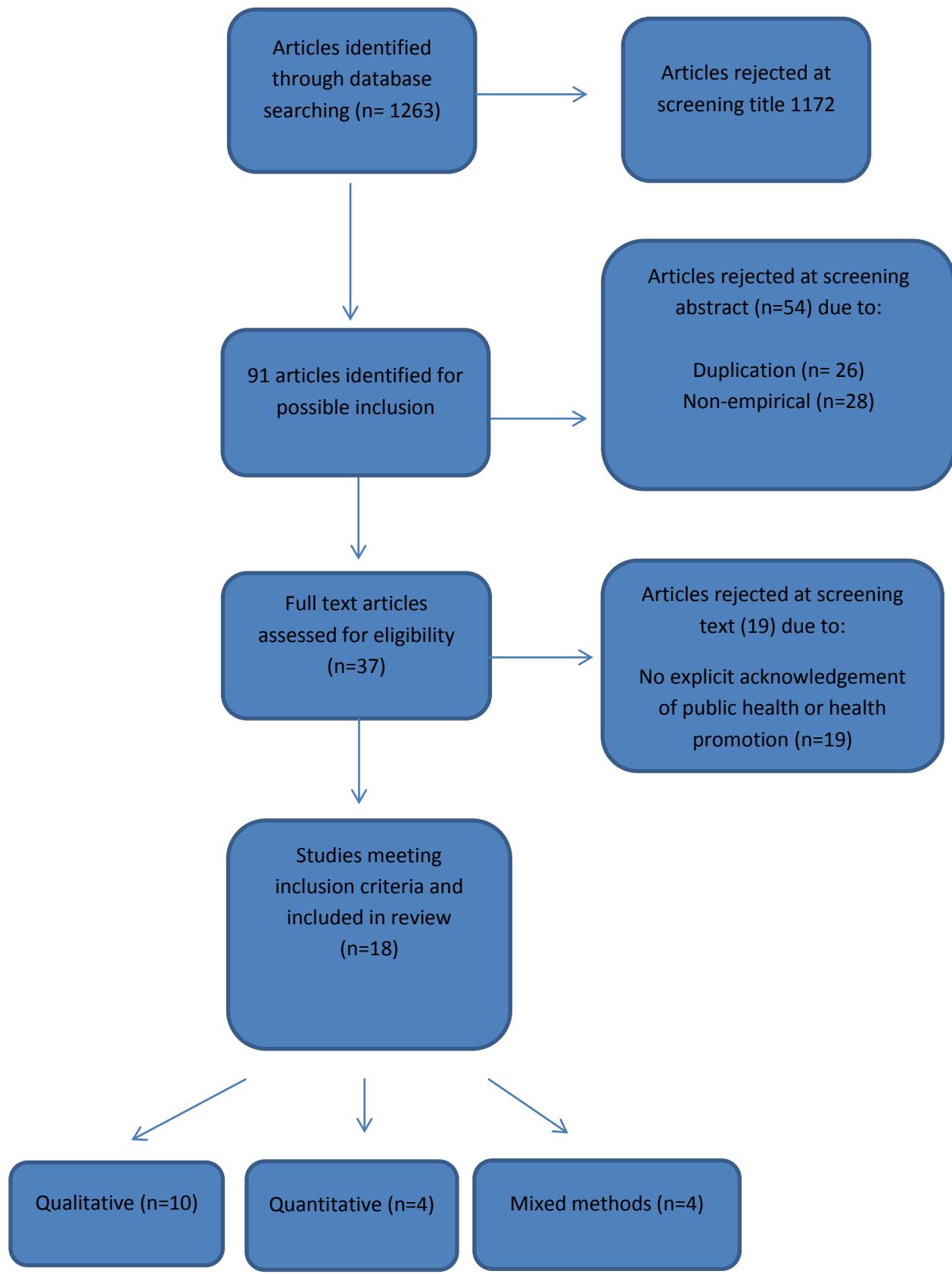


Figure 2.1: PRISMA flow diagram detailing selection of articles (Moher et al., 2009)

Table 2.3: Data extraction table for all included studies

| Author, Year, Country | Aim of Study | Participant s/sample/context | Study Design and Method | Key Findings | Study topic | Link to public health |
|-------------------------------------|---|--|--|--|---------------------|--|
| Aoun et al. 2014 Australia | To pilot test a survey associated with a theoretical public health model for bereavement support | 23 clients from 3 funeral providers 6-24 months post bereavement | Quantitative and qualitative data from a postal survey | Empirical support for the survey and the model was gained | Bereavement | The bereavement model proposed is population based – how different levels of interventions target different populations at risk |
| Bellamy et al. 2014 New Zealand | To explore older peoples experiences around bereavement support | 28 bereaved older adults from 3 different regions | Qualitative Telephone interviews | Family and friends play a pivotal supportive role in bereavement, as do community based organisations. The need for formal bereavement services was questioned by the majority of participants | Bereavement | The use of existing community supports in bereavement care was highlighted and links were made to Kellehear's health promoting approach to palliative care |
| Benzein & Saveman 2008 Sweden | To describe couples experiences of taking part in nurse-initiated health promoting conversations about existential issues | 6 couples, where one of them had advanced cancer and was receiving care from a palliative care home team | Qualitative Semi-structured interviews | Health promoting conversations about hope and suffering were found to be beneficial | Existential issues | Health promotion in palliative care was central to this study, and the context was palliative care |
| Gilson et al. 2013 International | To examine the influence of governments and health | 177 countries consumption of opioids in relation to other variables | Quantitative Multivariate regression | Few predictor variables can explain opioid consumption, although a | Opioid availability | Opioid availability was described as a key pillar of the WHO strategy for implementing |

| | | | | | | |
|--|---|--|--|---|--|--|
| | systems on opioid availability | such as human development index, palliative care infrastructure, health system resources and expenditure | | high human development index was associated with higher opioid consumption | | palliative care into health systems at country level. |
| Grant et al. 2011 Uganda, Kenya, Malawi | To describe local perspectives on the impact of three community-based palliative care interventions | 33 patients, 27 family carers, 36 staff, 25 volunteers and 29 community leaders Uganda, Kenya, Malawi | Evaluation study using interviews, observations and routine statistical data | Holistic care was delivered effectively and good deaths were achieved at home. Mobile phones facilitated access to clinical and social support networks | Evaluating community based interventions | The study focussed on access to oral morphine, and the impact of health systems on service delivery. Integration into policy and health systems was recommended as a public health approach |
| Horsfall et al. 2012 Australia | Nature, quality and effect of social networks – i.e. how they function | 94 carers representing 17 caring networks in New South Wales | Qualitative Creative methods (photo voice, network mapping and interviews) | Carers can successfully mobilise an informal networks of supports to care for the dying at home | Social networks | Social networks were described in terms of social models of care, social capital and community development. The background to the study referenced the work of Rumbold and Kellehear, known proponents of health promoting palliative care |
| Leonard et al. 2015 Australia | To analyse the caring networks of people with a terminal illness and identify changes over the time of caring | 77 people (in 9 focus groups) from the caring networks of 9 patients | Qualitative and quantitative (Social network mapping in focus groups) | Social networks were shown to increase in size, and the ties between members to strengthen over time. Core and peripheral networks were identified, and there was a diverse contribution to | Caring networks | End of life caring was articulated as contributing towards social capital, and clear links were made to Kellehear, community participation and development approaches to EOL care |

| | | | | care | | |
|---|---|---|---|--|---|--|
| Lewis 2014 Australia | To explore the nature of caring networks in lower socioeconomic populations | 16 patients and 6 informal carers in Western Sydney | Qualitative Semi-structured interviews | Identified networks were mostly inadequate to meet needs for care | Caring networks | Caring networks were described in terms of social capital and health promotion |
| Lindqvist 2015 Sweden/international | To explore the preferences for the surroundings in which death takes place | Visitors to a museum exhibition yielded 512 responses from 46 countries | Qualitative Questionnaire Single question, open-ended | Eight categories of preferred death surroundings are identified: familiar, larger than life, lone, mediated h, calm and peaceful, sensuous, green, and distanced death | Place of death (desirable surrounding for death and dying' p.2) | Health promoting palliative care was acknowledged as the framework for this study, and the exhibition was to promote public awareness around death and dying |
| Logie 2012 Zambia | To evaluate the implementation of an advocacy strategy to improve palliative care in Zambia | 8 palliative care organisations | Evaluation study Multiple methods (desk surveys, interviews, field trips) | The four pillars of WHO's public health strategy are vital to success. Ongoing financial support is needed to maintain palliative care infrastructure | Evaluating an advocacy strategy | The initiative under evaluation aimed to achieve country level improvements in access to palliative care, explicitly based upon the WHO public health strategy for palliative care |
| Lupu et al. 2013 U.S. | To quantify the courses available that teach palliative care from a public health perspective | Schools of Public Health in the U.S. | Quantitative Survey of the web | Only 6 out of 49 schools included palliative care content in their curricula | Education | This study advocates for a PHAPC, and more content on palliative care systems in schools of public health in the US in order to inform future policy experts |
| McIlpatrick et al. 2013 Ireland | To establish current awareness and attitudes of palliative care among the general | 600 responses from members of the public (17% response rate) Representativ | Quantitative Cross-sectional survey Structured questionnaire | Poor awareness of palliative care was found, especially among those with no | Public awareness | Explicit links were made to public health palliative care and health-promoting palliative care with references to the work of Kellehear. |

| | | | | | | |
|---------------------------------|--|--|---|---|---|--|
| | public | e sample | | previous exposure to hospice services | | Public experiences were articulated as being important to guide policy makers in shaping future awareness and educational strategies |
| McIlfatrick et al. 2014 Ireland | To explore public perceptions of palliative care in light of health promoting palliative care requiring more public ownership | 50 members of a community scheme in Northern Ireland | Qualitative Semi-structured telephone interviews | Experience generates understanding and targeted educational strategies are required | Public perceptions | Specific reference is made to Kellehear's health promoting palliative care, and low levels of public awareness were described as a challenge to the goals of a PHAPC |
| Mills et al. 2015 Australia | To explore community-based activities around end of life care that might link in with the philosophy of health promoting palliative care | 10 representative s from 8 local community groups with an interest in EOL issues in the Australian Capital Territory | Qualitative In depth semi-structures interviews and field notes | Themes identified from this study were practical support, respect and responsiveness, connection and empowerment. These were especially evident in groups where socialisation, peer support and normalisation were promoted. Community ownership was highlighted as being important | Community groups | It was clearly articulated that this study was concerned with health promoting palliative care and building community capacity in EOL care |
| Paul & Sallnow 2013 U.K. | To scope if the public health approach to EOL care is a priority for UK hospices | 146 services from four UK countries | Quantitative (only one open-ended question) Online survey | A public health approach to palliative care is a priority for the majority of UK hospices, and a range of work is being | The public health approach to palliative care | This study explored the uptake of the public health approach to palliative care in the UK |

| | | | | | | |
|------------------------------------|---|---|--|---|-------------------------------|--|
| | | | | undertaken in this area. There is a need for conceptual clarity around the public health approach to palliative care | | |
| Pizzi 2014 U.S. | To determine what professionals think about their work, and how does this thinking shape their practice | 12 hospice professionals from 4 disciplines and different organisations | Qualitative In-depth interviews | Promoting a good death was the overarching theme | Palliative care professionals | The conceptual framework for this study made specific mention of the Ottawa charter and discussed the links between health promotion and palliative care |
| Stajduhar et al. 2011 Canada | To examine the interpretation of family empowerment by home care services | 13 leaders from 3 health care agencies in British Columbia | Qualitative In-depth semi-structured interviews | Empowerment was seen as the long term goal of client/family self-care | Home care services | Empowerment was articulated as a principle of health promotion. The work of Kellehear and health promoting palliative care was referenced |
| Wilson et al. 2013 Canada | To determine public preferences for final days of life | 1203 adults living in Alberta Representative population-based sample | Quantitative Survey by telephone | Home is the preferred place for EOL care for most people living in Alberta. Public health interventions are needed to realise this preference. | Place of death | Exploring peoples preferences was described as taking a public health perspective on EOL care |

2.4 Data evaluation stage

Integrative literature reviews do not lend themselves to evaluating the quality of data. It is not possible to apply uniform quality criteria to such a diversity of research designs (Whittemore & Knafl, 2005). Therefore, the studies included in the review were not assessed for quality before analysis.

2.5 Data analysis stage

The analysis of the data from the literature took place over three stages, and is based on the flexible method for thematic analysis suggested by Braun and Clarke (2006):

- a. Data familiarisation
- b. Generating codes
- c. Developing themes

2.5.1 *Data Familiarisation*

Firstly, at the outset of the data analysis stage a data extraction table was developed to summarise and sort the salient information from each study (see Table 2.3), and then a thorough reading of each study was undertaken.

Of the 18 articles included ($N=18$), four were mixed methods ($n=4$), five were quantitative ($n=5$), and nine were qualitative ($n=9$). Of the mixed methods studies, two were evaluation studies ($n=2$). The dominant method for data collection in the qualitative studies was interviews ($n=7$). Amongst the quantitative studies, the use of surveys ($n=4$) was most prevalent.

Unsurprisingly, given that a PHAPC is well established in Australia, this country produced the highest number of published studies ($n=5$). The U.K produced three, while the U.S., Canada and Sweden each produced two. New Zealand and Zambia each produced one. One article concerned a group of three African countries (Uganda, Kenya, Malawi). One article was an international study in that it captured the views of international visitors to a museum exhibition in Sweden.

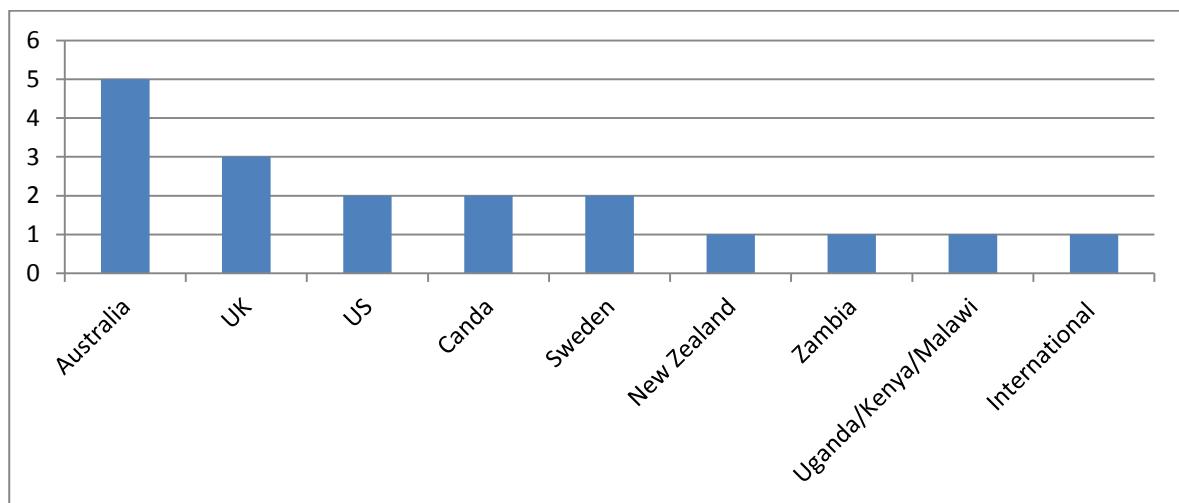


Figure 2.2: Chart showing the geographical origins of included studies

Social or caring networks were the subject of 3 of the studies. Bereavement, place of death and public awareness were each the subject of 2 studies. The remaining topics were each the subject of 1 study; they were: service delivery through community groups, service delivery through home care services, palliative care professionals, the uptake of a PHAPC, education, opioid availability and existential issues.

2.5.2 Generating codes

In the analysis of the literature, coding was based upon the words the authors associated with a PHAPC. Braun and Clarke (2006) refer to this as, “coding to identify a particular feature of the data set” (p. 18). In order to do this, extracts of data that included the search terms and their surrounding context were extracted from the texts. These extracts were then used to generate codes. See Appendix 1 for the coding scheme/codebook.

2.5.3 Developing themes

Thirdly, the codes were analysed for patterns in content or meaning (Saldana, 2009). These were grouped together into bigger sub-themes and themes. Three overarching themes were created, and these relate to how a PHAPC was conceptualised by the authors of the studies. These are now discussed:

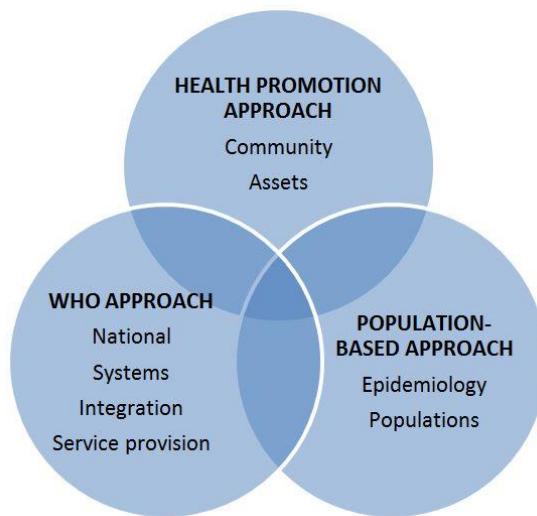


Figure 2.3: Themes: the articulation of a public health approach to palliative care

Theme 1 - Health promotion approach

This theme captures how twelve of the articles articulated a PHAPC (Bellamy, Gott, Waterworth, McLean & Kearse, 2014; Benzein & Saveman, 2008; Horsfall et al., 2012; Leonard, Horsfall & Noonan, 2015; Lewis, DiGiacomo, Luckett, Davidson & Currow, 2014; Lindqvist & Tishelman, 2015; McIlfatrick et al., 2013; McIlfatrick, 2014; Mills, Rosenberg & McInerney, 2015; Paul & Sallnow, 2013; Pizzi, 2014, Stajduhar et al. , 2011), and this was the dominant theme in the literature. Eleven of these studies used the actual words, ‘health promotion’ to frame their study, and the one study that did not (McIlfatrick et al, 2013), referenced the works of Kellehear on health promotion as the theoretical underpinning of a PHAPC.

Three sub-themes were identified within this theme. The first was that of *community*. Many of these studies referred to the importance of community in their descriptions and justifications of a PHAPC. Four studies promoted the use of community as providers of care over the further development of service provision (Bellamy et al., 2014; Mills et al., 2015; Lewis et al., 2014; Leonard et al., 2015). Horsfall et al. (2012) advocated for a move away from traditional health promotion where community members might be the passive recipients of education, to a more active model where they are agents of care provision through informal networks. Likewise, Paul and Sallnow (2013) argue for a move away from, “traditional public health measures” (p. 196) towards a community engagement approach where the community are active in their own care. The use and growth of social networks in end-of-life care was seen as a demonstration of a community development model in the study by Leonard et al. (2015). In all the studies, community appeared to refer to people or places or both. While Mills et al. (2015), Leonard et al. (2015) and Horsfall et al. (2012) all acknowledged the challenge of actually defining the word *community*, only Mills stated his particular definition in the context of his study. He writes, “in this context, communities are represented by existing or potential networks of individuals and groups that either share or have the potential to share common concerns or goals” (Mills et al., 2015, p.219). Interestingly, while academia has struggled to define *community*, Horsfall et al. (2012) and Leonard et al. (2015) both found that participants could easily and specifically define their understanding of the word when explored in terms of specific community networks, i.e. people.

The second sub-theme is assets. The codes that informed the development of this sub-theme all described asset-based rather than deficit-based thinking. In Benzein and Savemans’ (2008) descriptions of health promoting conversations, they highlighted the need for acknowledging resources and wellness as opposed to deficits and illness. Three of these studies (Horsfall et al., 2012; Leonard et al., 2015; Lewis et al., 2014), all Australian, were concerned with social capital, which Lewis et al. (2014) describe as a “relational resource” (p.2). It was reasoned that social capital in the form of caring networks furthers public good by meeting wider needs (Horsfall et al., 2012), contributes towards a de-medicalisation of death (Leonard et al., 2015), helps care for disadvantaged populations and adds to greater sustainability (Lewis, 2014). One study (Stajduhar et al., 2011) considered health promotion as an empowering model that decreased dependence on service delivery.

The third sub-theme had to do with the described *benefits* of a health promotion approach. The background to Linqvist and Tishelman's study (2015) describes how using opportunities to reflect on death and dying helps to break down taboos and increase awareness. These two benefits along with improving access to palliative care are identified as the outcomes of a PHAPC by McIlpatrick et al. (2013). Paul and Sallnow (2013) also cite examples of how community engagement methods have improved access to palliative care services. Two studies (Pizzi, 2014; Paul & Sallnow, 2013) mentioned holistic care as an intended outcome of health promoting palliative care. Other benefits mentioned included a good death (Pizzi, 2014), and positive changes in knowledge, attitudes and behaviours (McIlpatrick et al., 2014). Additional benefits of recognising and developing social capital have been described in the sub-theme assets.

Theme 2 – World Health Organisation (WHO) approach

All three studies (Gilson, Maurer, LeBaron, Ryan & Cleary, 2013; Grant, Brown, Leng, Bettega & Murray, 2011; Logie, 2012) that contributed codes towards this theme expressly acknowledge the use of WHO guiding documents and strategies related to palliative care. Two (Grant et al., 2011; Logie, 2012) of the articles were evaluation studies using mixed methods, and based in African countries. The other one (Gilson et al., 2013) was an international study, that used epidemiological methods to determine variables that might be associated with opioid availability. Given the recognition of the WHO, it is not surprising that all three studies considered their topic from a national perspective, and all three spoke of integration into the existing public health systems as being a goal to strive towards. Integration was also spoken of in terms of being incorporated into national policy (Grant et al., 2011). Both Logie (2012) and Grant et al. (2011) make reference to the national burden of palliative needs. Two articles articulated the need for better reach of service provision (Grant et al., 2011; Logie, 2012). Equitable service provision and the development of programmes were described by Grant et al. (2011) as being necessary and important. In Logies' study (2012), the issue of funding and sustainability was raised in terms of palliative care service provision.

One study (McIlpatrick et al., 2013) fitted into both themes of the *WHO approach* and *Health promotion approach*. This study advocated for incorporating elements from both paradigms, acknowledging

the need for a parallel approach ensuring that palliative care is more integrated into health service systems alongside a continued public health approach to palliative care in order to eradicate social taboos and ensure services are sought out when required (p. 6).

This was the only study that acknowledged dichotomous models, and from this extract it is implied that one approach is socially orientated and the other systems orientated.

Theme 3 – Traditional public health approach

At first it was considered to subsume this theme into the *WHO approach*, but upon reflection and further analysis of the texts, it was decided to keep this theme separate. The main reason for this decision was that

three studies (Aoun, Breen, Rumbold & Howting, 2014; Lupu, Deneszcuk, Leystra, McKinnon & Seng, 2013; Wilson, Cohen, Deliens, Hewitt & Houttekier, 2013) simply did not fit comfortably into either of the first two themes. Of these three studies, two made very limited reference to the WHO strategic documents related to palliative care (in comparison to those allocated to *WHO approach* theme), and one made no mention of WHO at all. Neither did these three studies fit into the first theme *health promotion approach* since they made no reference to health promotion. Thus the third theme, a *population-based approach* was generated using the codes from these three articles.

A population-based approach was upheld by all three studies. One was a population-based survey (Wilson et al., 2013), one advocated this view in its' description of a public health model (Lupu et al., 2013) and one was a pilot study that recommended the results be tested by a larger population-based study (Aoun et al., 2014). Epidemiology, research and policy are described by Lupu et al. (2013) as the 'tools of public health' necessary for a PHAPC (p. 1583). In the study by Wilson et al. (2013) which considered public preferences on the place for end-of-life care, epidemiological concepts such as predictive variables were considered. A good home death was described as the desirable outcome of public health interventions at the end of life (Wilson et al., 2013). The developments of service provision options as well as the development of community capacity are acknowledged in the study by Aoun et al. (2014). This study also recognised the importance of cost savings and equity in allocating resources in the context of a public health model.

2.6 Discussion of findings

The three themes identified in this literature review may be thought of as three different paradigms of a PHAPC. It is worth noting that the first paradigm is the dominant articulation of a PHAPC in the literature. This is the *health promotion approach*. Community empowerment, assets-based thinking and the benefits of a PHAPC were main ideas associated with this theme in the studies. This paradigm is what this thesis is primarily concerned with, and it resonates with the definition of the PHPCIA described in chapter one. Many of the proponents of this school reference Allan Kellehears' model of health promotion, which he himself describes as an essentially social model (Kellehear, 1999b). This approach is similarly called health promoting palliative care (Kellehear, 1999a, Kellehear, 1999b).

Noteworthy is the prevalence of the term 'social capital' in the articles that contributed to the *health promotion approach* theme, in particular to the sub-theme of assets. Social capital is a concept growing in popularity within the social science literature (Fine, 2004). It has also been proposed as a potential model to support well-being in palliative care (Lewis et al., 2013). The term neatly covers a range of beneficial social links within groups, between groups and across hierarchies. However, as a concept, it has been criticised on a number of points including its' lack of clear definition; the simplistic use of the term to cover an extensive range of phenomena; its inability to recognise cross-cutting links of gender, ethnicity and class; and the implied meaning of the word 'capital' being that it only generates positive outcomes (Fine, 2004).

The close association of this imprecise concept with a PHAPC may potentially add further divergence in understanding the *health promotion approach*.

The second paradigm is that which I have labelled the *WHO approach*. This set of ideas seems to reflect more accurately the WHO Public health Strategy for Palliative Care (Stjernsward, 2007). This strategy highlights four essential pillars for improving and integrating palliative services into country health systems, namely policy, drug availability, education and implementation (Stjernsward, 2007). These features, specifically integration, a health systems focus, the importance of policy and opioid availability were clearly associated with a PHAPC in the three studies linked to this theme or paradigm.

These first two paradigms appear to have different foci or goals. Those studies reflecting the *WHO approach* are concerned with integrating palliative care into health systems, at country level predominantly, and therefore service coverage and provision are core concerns. The studies linked to a *health promotion approach* talk much about social empowerment and the de-medicalisation of death, and this seemingly at a community level. While this does show different emphases, it cannot be said that these two paradigms are mutually exclusive, because arguably the goals of one would support reaching the goals of the other. Community empowerment and mobilisation would certainly improve reach, as has been demonstrated elsewhere (Twycross, 2007). Also, it must be acknowledged that although not made clear in the studies included in this review, social participation and community ownership is unambiguously upheld in the WHO Public Health Strategy for Palliative Care (Stjernsward, 2007), and therefore this is common ground between these paradigms.

The third way, in which palliative care issues are referenced in the literature, is simply from a population perspective often relying on the science of epidemiology for evidence. This may be described as a *population-based approach*. The studies that reflected this conceptualisation made no explicit link to health promotion or the Ottawa charter, and none to the WHO public health strategy for palliative care.

2.7 Conclusion

This integrative literature review analysed eighteen journal articles that expressly identified their studies as nested within a PHAPC. A thematic analysis of the texts has shown that a PHAPC was conceptualised by the authors of these studies in three different ways. The dominant paradigm was that of a *health promoting approach*, the other two less dominant paradigms were labelled the *WHO approach* and the *traditional public health approach*. This review highlights that there are indeed conceptual challenges for understanding a PHAPC, in that it may be framed or understood in different ways. It is the prevailing view of the *health promoting approach* that is central to this thesis. The findings from this literature review have contributed to the development of conceptual thinking around a PHAPC internationally, having been published in the journal *Progress in Palliative Care* in June 2016, a copy of which may be found at Appendix 8.

CHAPTER THREE: METHODOLOGY AND METHOD

3.1 Introduction

The first chapter of this thesis describes the background for this study exploring the status of a public health approach to palliative care in New Zealand, while chapter two confirms that there are indeed conceptual challenges for understanding the approach. The current chapter moves into the practical aspects of the study. After considering the philosophical foundation upon which the study was built, the methods used for data collection and analysis will be outlined.

3.2 Methodology

In research, philosophy refers to the assumptions that the researcher brings to the research process (DePoy & Gitlin, 2011). These assumptions, also known as world views or paradigms, take place around two key questions:

- What is reality/truth? (ontology)
- How do we come to know reality/truth? (epistemology)

It is important to recognise these assumptions and articulate them upfront as they are likely to influence the process and outcome of the research (Creswell & Plano Clark, 2011).

Creswell and Plano Clark (2011) describe four main research philosophies or paradigms. The first is *post-positivism*, which is characterised by reducing the study into its' component variables and determining how these variables interrelate, using observation and measurements. Truth is thought to be fixed and observable. Quantitative studies are often under-pinned by this paradigm. The second paradigm *constructivism*, holds that truth is constructed by people and context. Many qualitative studies assume this world view. Thirdly, a *participatory* paradigm is concerned with actively improving society. Studies sitting within this assumption are often characterised by a concern with politics, power and justice. Quantitative and qualitative studies may employ this worldview, where truth is understood to be shaped by context. Finally, *pragmatism* is more concerned with the research question and consequences than the research methods. In light of this, multiple methods may be used, and therefore this world view is commonly aligned to mixed method studies (Bryman, 2006). The objective of using a mixture of methods is often pragmatic, in other words, "whatever methods are considered useful for the attainment of the project's objectives" (Taylor, Kermode, & Roberts, 2006, p. 421). Truth is viewed as, "relative and purposive" (DePoy & Gitlin, 2011, p. 30). Pragmatism is a distinct paradigm in itself, however it is recognised that thinking and actions from either or both positivist and constructivist paradigms are drawn upon in the research process (DePoy & Gitlin, 2011).

This study resonated most closely with a world-view of pragmatism. Foremost in my mind was the research question itself: what is the uptake, nature and understandings of a PHAPC by hospices within New Zealand? This focus on the question is typical of a pragmatic approach (Creswell & Plano Clark, 2011). The question for this thesis had different elements to it, namely the uptake, the nature and the understandings around the PHAPC. These elements were thought to be best answered using different methods, drawing on positivism and constructivist assumptions to determine the truth. This practical selection of methods also reflects pragmatism (Creswell & Plano Clark, 2011).

3.3 Method

Method refers to the *means* of generating knowledge (Taylor et al., 2006). A mixed method approach, using both quantitative and qualitative methods, was chosen for this study based on the following two pragmatic reasons:

- i. Mixed methods can be used to answer **different questions** (Bryman, 2006). In this case, the research question was multi-faceted, and required a different means of answering it.
 - To establish the *uptake and nature* of a PHAPC was thought to be best answered by using quantitative methods.
 - To gauge current *understanding* of a PHAPC (and further explore the nature of a PHAPC) was thought to be best answered using qualitative methods.
- ii. Mixed methods are useful when two methods add to the **completeness** of a study or are better able to provide an **explanation** of the results (Bryman, 2006). In this study, it was anticipated that a combination of qualitative and quantitative data, would provide a more complete picture of public health approaches in New Zealand. There was also the possibility that the quantitative results might be better understood in the light of the qualitative data gathered.

The specific mixed methods chosen were an online survey and semi-structured telephone interviews. These will be discussed in greater detail further on in this chapter.

3.4 Rigour

In the design of this study, careful consideration was given to rigour. Rigour refers to, “the procedures that enhance and are used to judge the integrity of the research design” (Depoy & Gitlin, 2011). The reason rigour is important in research is to ensure that the findings or results from a given study may be trustworthy (Taylor et al., 2006).

Quantitative and qualitative methods consider different aspects to be important in rigour. Since this study was a mixed-methods study, a variety of considerations were applied to each method of the data collection and analysis to improve rigour:

i. Triangulation

- Applies to quantitative and qualitative methods.

Triangulation involves measuring a single concept in a number of different ways (Payne, 2007). The combination of qualitative and quantitative research methods may be viewed as one form of triangulation – called methodological triangulation (Flick, 2011). This was not the explicit reason for choosing mixed methods for this study, rather a mixed methods approach was selected as the best means of addressing the research questions posed. However, it was anticipated that being able to combine and compare the quantitative results from the survey with the qualitative results from the interviews would certainly add rigour to the findings.

ii. Audit trail

- Applies mostly to qualitative methods.

Throughout this study I kept a detailed notebook of decisions made, versions of work with tracked changes, and copies of correspondence with my research supervisor and others. Such an audit trail is evidence of the thought processes and rationale informing key decisions during the research process (Payne, 2007). This transparency allows scrutiny by others should queries arise (Taylor et al., 2006).

iii. Reflexivity

- Applies mostly to qualitative methods.

The researcher was aware of her subjectivity in the analysis of the qualitative data. This is acknowledged and indeed valued in qualitative studies (Holloway & Wheeler, 2010). Conducting and transcribing the interviews allowed me to experience the atmosphere and tone of the interviews. For example hearing the excitement or frustration in the participant's voices, allowed me to interpret their meanings more accurately. Tracking my own comments and thoughts on the transcripts helped me to note, but also separate my own interpretations from the words of the participants. Although such subjectivity is important, all efforts were made to identify and acknowledge personal bias during analysis and discussion of the qualitative findings. My personal experience of grappling with understanding a PHAPC is made clear in chapter one. Careful attention was placed on not assuming or inferring this challenge onto the participants. Repeated examination of the transcripts during the multiple rounds of coding helped to ensure the context and meaning of the participants was retained, and minimised assumptive interpretation.

iv. Debriefing

- Applies to quantitative and qualitative methods.

As a student, I had the constant support of my supervisor. This supervision ensured that not only was the research process clear and progressive, but personally I had the opportunity to talk through concerns and check ideas. A further benefit was that it added strength to the findings as the data were discussed until both parties reached consensus on the interpretation.

v. Transferability

- Applies mostly to quantitative methods.

Also known as external validity or generalisability, this refers to the ability to generalise quantitative results beyond the sample to the wider population in view (Taylor et al., 2006). Transferability depends on the sample size attained and therefore efforts were made to maximise response rates and ascertain any participation bias, and in the case of a small population such as this ($N=28$) it was important to reach as high a response rate as possible.

vi. Validity

- Applies to quantitative and qualitative methods.

Internal validity refers to the ability of the research results being able to answer the question (Taylor et al., 2006). In the quantitative phase of this study, validity was bolstered by using a survey tool that had already been used and published (Paul and Sallnow, 2013). In the qualitative phase of this study, internal validity was enhanced by member checking of the interview transcripts. This was a means of affirming the accuracy of the data before analysis began.

vii. Reliability

- Applies mostly to quantitative methods.

External reliability refers to stability or repeatability; in other words whether or not a quantitative study would yield the same results if repeated (Hardy & Bryman, 2004; Taylor et al., 2006). The fixed and systematic processes employed in quantitative research are thought to enhance this likelihood and therefore the reliability or truth of the results. Relating to this study, the purpose of the online survey was to measure activities and thoughts at a set point in time, so reliability is not applicable or necessary. Indeed the aim of the study was only to measure the *current* uptake of a PHAPC. However, the design of the survey was such that the closed-ended questions if factually answered would theoretically remain true for a limited period of time.

Internal reliability refers to consistency and is gained when the same concept, measured at different points on the same instrument, results in the same answer (Hardy & Bryman, 2004). The survey tool chosen for use in this study allows for such internal reliability checks.

3.5 Design

Creswell and Plano Clark's (2011) propose six main categories of mixed methods designs based on the timing of the data collection, the interaction of tools, priority given to methods, and the mixing of results.

Based on these classifications, this study employed a **convergent parallel** design.

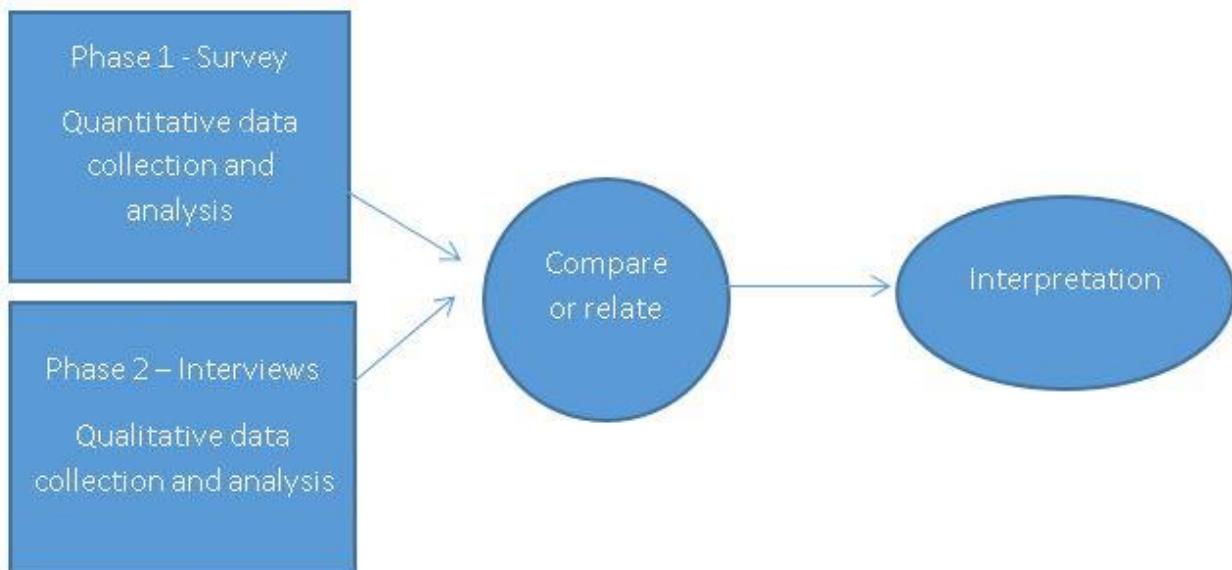


Figure 3.1: The convergent parallel design (Creswell & Plano Clark, 2011, p. 69)

The convergent parallel design was chosen because it was thought to be best suited to addressing the various elements of the research questions. This design consists of a quantitative phase and a qualitative phase which are now discussed.

Phase one was an online survey. The aim of this phase was to gather basic quantitative data on the *uptake and nature* of PHAPC. The strength of quantitative data is that it has the potential to establish trends in a wider population, in this case the hospice sector in New Zealand (Creswell & Plano Clark, 2011).

Phase two involved conducting semi-structured telephone interviews, in order to investigate *understandings* of a PHAPC and related concepts. It was anticipated that the qualitative data would add depth and detail to the quantitative findings (Creswell & Plano Clark, 2011).

The anticipated outcome was that the combined information from both phases would create a fuller picture of the phenomenon of a PHAPC in New Zealand. The questions in the survey and the interview schedule were intentionally different, in that each tool was collecting information on a different concept. Equal priority was given to phase one and phase two. Data collection for each phase overlapped. Data from each phase were analysed separately first before any comparisons or merging for interpretation.

With regards participants, Creswell and Plano Clark (2011) suggest that it is best to use the same participants for the quantitative and qualitative data collection, if one aims to compare the data collected. In

this study, the interviews were conducted with smaller sub-set of the survey participants, so essentially data has been collected from the same set of people and therefore data comparisons could be made in the analysis.

3.6 Ethical Considerations

The ethical issues identified as pertaining to this study were confidentiality, consent and autonomy (Pera & van Tonder, 2005). These are now discussed:

i. Confidentiality:

The population of hospices in New Zealand is relatively small and relationships close-knit. It was therefore considered important to ensure that the hospices' identities were kept confidential, and that their views were not able to be linked to themselves or their hospices. In order to ensure this, careful consideration was given to how the findings of this study were to be articulated, and it was made clear that no hospices or individuals would be identifiable in any dissemination of findings. In addition hard and electronic copies of the data were stored securely and were accessible only by myself and my supervisor.

ii. Informed and voluntary consent:

The participant information sheet (PIS) was sent to all potential participants informing them of the detail of the study, and also inviting any queries or concerns to be raised with either the student or the supervisor. With regards consent for the online survey, the PIS explained that participation in itself implied consent. With regards consent for the telephone interviews, only participants who willingly and voluntarily shared their contact details with the researcher (at the end of the online survey), were approached to take part in the interviews. Prior to the interviews, a consent form was emailed to the participants, signed and emailed back to me. A copy of the PIS and consent form may be found in Appendix 3 and 4 respectively.

iii. Autonomy - The participants right to withdraw:

Withdrawal from the short online survey was not considered to be an issue. However, should a hospice contact me and wish to withdraw their submission, the PIS explained how they may do so and within what time frame. This was to be done by them describing their submission, which would then be deleted and/or destroyed by shredding. The PIS also detailed the participant's right to withdraw at any stage of the interview without the need to give a reason. In addition, participants were informed in the PIS that they may withdraw their data up to one month post interview, which would then be deleted and/or destroyed by shredding.

4. Conflict of interests:

No significant conflicts of interest were anticipated for this study. However, a decision was made to intentionally excluded the hospice I worked at to avoid a potential conflict of interest.

The ethics application for this study detailed the issues perceived to be of importance, and how these were intended to be mitigated. The application was submitted to the Auckland University Human Participants Ethics Committee and approved on the 3 May 2016 for a period of three years. A copy of the approval letter may be found in Appendix 2.

3.7 Phase 1: Online survey

An online survey was the method selected to gather data to gauge the *uptake and nature of a PHAPC* by hospices in New Zealand. Surveys are typically a set of questions whose answers are analysed and presented statistically (Addington-Hall, 2007). They are well suited to measuring certain characteristics within a chosen group or population (DePoy & Gitlin, 2011). A survey may be administered face to face, by post, over the telephone, or – as in this case, on-line over the internet. The benefits of an on-line survey are that they can be administered at very little or no cost and the data can be gathered and analysed relatively quickly. One of the chief limitations of online surveys is that only certain people, i.e. those with the required resources, have access to the internet, and this limits the response rate and may introduce bias (Addington-Hall, 2007). However, this was not considered to be an issue for this study, as the specific population in question, namely CEO's or senior leaders of hospices, were known to all have the resources required to access to the internet.

3.7.1 Data collection for Phase 1 - Survey

3.7.1.1 The tool

As mentioned, a survey scoping the uptake of a PHAPC in the UK was published in 2013 (Paul & Sallnow). Since it was developed to answer a very similar question to that posed by this study, the authors of the UK survey were contacted and asked for their permission to use the tool in New Zealand. The authors gave permission via email on the 27th November 2015. A copy of the permission email and the original UK tool may be found in Appendix 5 and 6 respectively. Minor changes were made to the tool to make it relevant to the specific New Zealand context, for example changing options of geographical location. One new question was added and related to intentional work with ethnic groups. My supervisor and I deemed the tool simple to understand and appropriate to the hospice sector prior to being put online.

Using the UK survey tool had distinct advantages. Firstly the tool had already been piloted, tested, and the results published in a peer-reviewed journal (Paul & Sallnow, 2013). This was thought to aid internal validity, a key consideration in survey research (Addington-Hall, 2007), as has been discussed in the section on rigour. Secondly, repeating the survey meant that country comparisons might be made in the data analysis. The comparison between the UK and New Zealand data provided the opportunity to benchmark New Zealand with what is seen as one of the world leaders in hospice and palliative care service provision.

The survey consisted of four closed-ended questions, gathering categorical data on geographical location, population served, the type of services offered, and whether or not a PHAPC was a priority to their hospice. Two open-ended questions asked respondents to describe initiatives undertaken explaining why they felt certain activities were successful, and the opportunity to comment on the role of hospices in relation to social approaches to EOL care. The survey was put onto a free online tool called Survey Monkey (www.surveymonkey.com). Survey Monkey was chosen because it is a tool familiar to many, as well as being intuitive and easy to use. The survey monkey account was created by myself and was only accessible by a secure password. Screen shots of how the survey looked online, are shown in Figure 3.2 which flows over the next two pages.

Figure 3.2: Copy of the online survey

The uptake of a public health approach to palliative care by hospices in New Zealand

This survey consists of 6 questions and should take about 10 minutes to complete. Your responses will not be anonymous, but will be kept confidential. Neither you nor your hospice will be identified in any future report or publication on these survey findings.

This survey has been approved by the University Of Auckland Human Participants Ethics Committee on 3/5/20 for a period of three years. Reference number 016999.

Next

1. Where is your hospice located?

North Island
 South Island

2. Describe the areas served mostly by your hospice:

Rural
 Urban
 Mixed

3. Which of these services does your hospice offer?

Inpatient beds
 Home care
 Day hospice

4. There has been recent interest in social approaches to end-of-life care, such as *health promoting palliative care* and the *compassionate communities* movement in the UK. Is this something that is a priority for your service?

Yes, this is a current priority
 No, not at this time, but possibly in the future
 No, we do not have the resources to take this forward
 No, this is not within the remit of our hospice services

5. Has your service undertaken any of the following projects? Could you answer yes or no, and describe the activity briefly in the space provided.

Working with local schools

about loss, death, dying
and/or hospice care?

Providing public education
and awareness at events?

Attending community events
as a hospice such as
markets or festivals?

Working with faith groups
around loss, death, dying
and/or hospice care?

Working with specific ethnic
groups around loss, death,
dying and/or hospice care?

Supporting community
dialogue about end-of-life
issues?

Engaging with local media on
issues related to loss, death,
dying and/or hospice care?

Engaging with local
businesses on issues related
to loss, death, dying and/or
hospice care?

6. If you have ticked any of the boxes above, please say which projects you felt were most successful and why?

7. Please feel free to add any comments you have on the role of hospices in relation to social approaches to end-of-life care (such as compassionate communities or health promoting palliative care).

I would like to follow up a small number of these survey responses by telephone, to find out a little more about your perceptions and support for these new approaches. Such an interview is voluntary and would take about 30 minutes at a time that suits you. The interview will be confidential. Neither you nor your hospice will be identified in any future report or publication. If you are happy to be contacted for such an interview, please leave your contact details below.

8. Your contact information:

Name

Hospice

City/Town

Email Address

Phone Number

Thank you for your time in completing this survey. Should you have any concerns or queries related to this, then please contact Colleen Dempers on 06-8787047 or Merryn Gott on 09 923 1655.

Prev

Done

3.7.1.2 Participants

In surveys, the aim is to achieve results that will be representative of the population in question (Depoy & Gitlin, 2011). The sample of participants chosen is therefore critical to achieving this goal of generalisability. In this study, the sampling frame, or list of all the possible participants, was all the CEO's of all the hospices in New Zealand. Typically from this sampling frame, a smaller set of participants is randomly selected, in other words each participant has an equal chance of being selected (Addington-Hall, 2007). However, in this case, the number of CEO's was only 28, and therefore it was deemed feasible to include the entire sampling frame in the invitation to participate, with no need to select a smaller sub-group. The participants chosen for the survey was therefore a whole population sample including all the hospices in New Zealand that affiliate to national umbrella body Hospice New Zealand – excluding the researchers own hospice (n=29-1). This equates to a national survey in terms of hospice services. The survey results hoped to generate results that would accurately reflect the national uptake of a PHAPC.

3.7.1.3 Implementation

The response rate of any survey impacts on its' ability to generate truly generalisable results. If the response rate is poor, this impacts negatively on the findings, particularly because non-responders may be significantly different from those who did respond. Such participation bias may mean that the inferences towards the population or group in question are inaccurate (Addington-Hall, 2007).

In order to maximise the response rate for this survey, the support of Hospice New Zealand was sought. As the umbrella body for all the hospices, the organisation has significant influence. Hospice New Zealand, on behalf of the student, sent the first email to all the CEO's of the hospices on the 10th May 2016. The email encouraged hospices to participate, and contained an embedded link to the on-line survey. The PIS with all the information about the study was an attachment to this email. After two weeks a reminder email was sent out to all those hospices that had not yet responded. One month later the survey was closed.

3.7.2 Data analysis for Phase 1 - Survey

As per convergent parallel mixed-method designs, the data from the survey were analysed separately from the data from the interviews (Creswell & Plano Clark, 2011).

Since the survey comprised both- closed-ended and open-ended questions two different methods of data analysis were necessary to analyse the answers. These methods are now described for Phase 1.

3.7.2.1 Basic descriptive statistics

If the aim of a survey is to identify and predict relationships between variables, then the survey must collect data on the multiple variables of interest. Inferential statistics are then applied to determine the strength of these relationships (DePoy & Gitlin, 2011). However, the aim of this survey was simply to examine the uptake and nature of a PHAPC, rather than to explore relationships between two (bivariate) or more (multivariate) variables. Furthermore, the size of the population in view (New Zealand Hospice leaders) as well as the anonymous nature of the survey, both limited the potential number of variables gathered. Therefore descriptive statistics were selected as the most appropriate level of analysis.

Basic descriptive statistics employs a variety of techniques to reduce and display data. For this survey, *frequency distribution* was the chief technique used. This technique was deemed most suitable because of the type of data gathered – that being categorical or nominal data. Categorical data is comprised of answers that fit into mutually exclusive categories, with no particular order or ranking (DePoy & Gitlin, 2011). Four of the survey questions (Questions 1-4) were closed-ended and participants had to select their answers from pre-determined categories. Data from these survey questions was reduced into single numerical scores which were counted. The reduced data were then presented as frequency distribution tables and charts that described and summarised the original data (DePoy & Gitlin, 2011).

3.7.2.2 Content analysis

Two of the survey questions (Question 5 and 6) were open-ended, yielding narrative text answers. The method best suited to analysing these answers was considered to be *content analysis*. This method is not concerned with meanings of whole texts; rather it reduces text into smaller units of words or phrases which are counted for frequency (Flick, 2011). According to the description of content analysis given by Payne (2007), words or phrases were selected to form pre-determined categories or codes, and then the frequencies of their use in the text were counted.

It must be noted that one question (Question 7) merely collected comments from respondents. These could not be allocated pre-determined codes, and therefore the ideas contained in these answers were simply summarised. However, the other two questions were allocated pre-determined codes to allow content analysis to be carried out. The selection of the predetermined codes for each of these questions is now discussed.

i. Content analysis for Question 5(b):

Question: Has your service undertaken any of the following projects? Could you answer yes or no, and describe the activity briefly in the space provided.

Content analysis of this question relates to the second half of the question (in bold above). It was intended that the provided description of the project would allow me to determine the nature of the work done. In order to determine this, the spectrum of community engagement recommended by Rosenberg et al (2016) was applied, that being the conceptual model proposed by Sallnow and Paul (2014). This spectrum acknowledges that work done under the banner of a PHAPC often sits on a continuum of community engagement. The spectrum seats true empowering work led by the community on the far right, and service-led work where the community are passive recipients on the far left, with a range of options in the middle. This range of strategies for community engagement is from left to right: inform, consult, co-production, collaborate and empower.

A number of key ideas have been suggested by Sallnow and Paul (2014) as guidelines to assist in determining if an activity might be considered community engagement at all, and if so what its position on the spectrum might be. It is these ideas that guided me in allocating the narrative text answers into the predetermined categories required for content analysis. These guiding principles are now discussed.

Firstly, it must be determined if an activity is community engagement in the first place. If the central concern of the activity is the clinical care of the patient and family then the activity more likely to be core service provision rather than community engagement. In addition, if the community is viewed as the place of service delivery, then the activity is simply service provision *in* the community setting and not community engagement. True community engagement must work *with* the community with the aim to improve the community's experience of death and dying.

Secondly, different activities will have varying levels of power to bring about change, and this is what will determine their general position on the spectrum suggested by Sallnow and Paul (2014). In general, if the chief aim of the activity is to benefit the service, or users of the service, with only marginal benefits for the community then again the activity sits to the left of the spectrum at best, for example fund-raising and traditional volunteering. Whereas an activity carried out in partnership with the community, intentionally aimed to benefit the wider community will be positioned more to the right of the spectrum. An example here might be death literacy work, which specifically aims to increase knowledge and skills in people and communities, around end of life issues (Noonan, Horsfall, Leonard & Rosenberg, 2016).

Thirdly, in order to allocate the activities into more specific positions on the spectrum, the authors give further suggestions for consideration (Sallnow & Paul, 2014). These include the nature of participation (for being

active or passive), the nature of partnership (in making decisions and carrying out the work), the nature of power-sharing (in leading the work), and the nature of communication (one-sided or two-way).

In summary the principles outlined above guided me to allocate each described activity a position on the spectrum. These different types of community engagement along the spectrum formed the pre-determined codes to which textual answers to question 5b were allocated and then counted.

Table 3.1: Codes for Question 5b

| Pre-determined codes for Q5b |
|------------------------------|
| Inform/consult |
| Co-production |
| Collaborate |
| Empower |

Table 3.2: Example of coding Question 5b

| Respondent# | Response | Initial coding | Pre-determined code |
|-------------|---|--|---------------------|
| 13 | <i>Yes – staff have offered information at courses run by churches</i> | Offering information (community are passive recipients) | Inform |
| 3 | <i>Yes. Rabbi and members of the Jewish community regularly participate in sharing their rituals at hospice</i> | Participation and sharing (community is more active) | Co-production |

ii. Content analysis for Question 6 (a)

Question: If you have ticked any of the boxes above, **please say which projects you felt were most successful** and why.

In answering the first part of this question (in bold above) participants had to describe the activities they had found most successful. The codes for the answers to this question were simply the set of options listed in the previous question (5). Text answers were allocated to one of these codes and then counted.

Table 3.3: Codes for Question 6a

| Pre-determined codes for Q6a |
|--|
| Working with local schools about loss, death, dying and/or hospice care |
| Providing public education and awareness at events |
| Working with faith groups around loss, death, dying and/or hospice care |
| Working with specific ethnic groups around loss, death, dying and/or hospice care |
| Supporting community dialogue about end of life issues |
| Engaging with local media on issues related to loss, death, dying and hospice care |
| Engaging with local businesses on issues related to loss, death, dying and hospice care |
| Attending community events as a hospice such as markets or festivals |

Table 3.4: Example of coding for Question 6a

| Respondent# | Response | Initial coding | Pre-determined code |
|-------------|--|----------------|----------------------------|
| 6 | <i>We constantly promote (name of) food festival - opportunities to engage with public and businesses.</i> | Festival | Attending community events |
| 11 | Media still probably has the most impact- especially a mixed media approach | Media | Engaging with local media |

iii. Content analysis for Question 6(b)

Question: If you have ticked any of the boxes above, please say which projects you felt were most successful and why.

The second part of this question (in bold above) is in view here. The *reasons* that hospice leaders gave for the success of the projects they described, were taken as indicator of the nature of the activities described. As discussed, Sallnow and Paul (2014) have stated that the aim of true community engagement activities is to benefit the community by developing community capacity. Therefore the codes prescribed for this set of answers, were essentially to detect if the reasons given for success were deemed beneficial to the hospice or to the community or to both. Following the same pattern used to content analyse the previous textual answers, these codes were then counted.

Table 3.5: Codes for Question 6b

| Pre-determined codes for Q6b |
|-------------------------------------|
| Hospice gain |
| Community gain |
| Both gain |
| No reasons given |

Table 3.6: Example of coding for question 6b

| Respondent# | Response | Initial coding | Final code |
|-------------|---|--|----------------|
| 2 | <i>Hard to measure success. I think speaking engagements at service clubs etc are the best opportunities to influence - they are a captive audience and have the ability to spread our word</i> | 'Captive audience', and 'spread our word' imply hospice gain | Hospice gain |
| 8 | <i>Cultural responsiveness group - enabled engagement with Māori and Pacific people so any initiatives based on what is most appropriate</i> | Gain knowledge of what's appropriate i.e. for the community | Community gain |
| 1 | <i>Conversations with groups about end of life during Awareness Week. Not large numbers but worthwhile conversations.</i> | Conversation implies two-way dialogue. Groups are assumed to be various sectors of society/community. Worthwhile – the implication is that the conversation is worthwhile for both parties | Both gain |

3.8 Phase 2: Telephone interviews

To add depth to the survey findings and to explore current **understandings of a PHAPC** and closely related key concepts, semi-structured telephone interviews with a smaller sample of hospice leaders were conducted. Interviews were deemed the best way to answer this aspect of the research question. Qualitative interviews typically encourage participants to tell their experiences or understandings in an unconstrained way (Taylor et al., 2006). The interviewer is able to probe in order to solicit a response deemed rich enough (Flick, 2011).

In line with the pragmatic philosophy informing the study, and given the time constraints of the CEO's and the geographical distance between all the hospices, it was thought telephone interviews would be most convenient and cost-effective for all concerned. Individual interviews were selected over focus group discussions because they would allow individuals to express their understandings without the potential of being influenced by others. Payne (2007) states that telephone interviews are appropriate for interviewing busy professionals. Furthermore, a recent New Zealand study exploring the experiences of those taking part in semi-structure telephoned interviews, has confirmed the value of this method in qualitative inquiry (Ward, Gott, & Hoare, 2015). The findings from this study particularly highlight the user-friendly and pragmatic benefits of telephone interviews.

3.8.1 Data Collection for Phase 2 – Telephone Interviews

3.8.1.1 The interview guide

In semi-structured interviews, an interview schedule or guide is prepared beforehand, and consists of a number of open-ended questions. This guide is there to ensure consistency in the questions being posed to participants, to help initiate dialogue and to help keep the interview within the remit of the research question (Flick, 2011). A copy of the interview guide may be found at Figure 3.3.

In this study, the questions were designed to allow exploration of the participants' understandings of:

- Understandings of a PHAPC in general
- Understandings around community engagement – a method employed by a PHAPC
- Understandings of social network approaches – a method employed by a PHAPC
- Allow further insight into the nature of a PHAPC

The pragmatic nature of the philosophy underpinning this study, gave me the liberty to apply the principle of constant comparative analysis to the interview schedule, even though this is typically limited to studies based upon Grounded Theory. Constant comparative analysis allows one to test or explore perceptions raised by one participant with other participants in future interviews, even if the item was not originally a part of the

interview schedule (Silverman, 2005). Essentially it allows the researcher to refine the interview guide along the way, while collecting data. In this case, particular topics of interest raised by early participants were added to the schedule as the interviews progressed; these were around exploring the concepts of *death cafes*, the *over-medicalisation of death* and *social isolation amongst older people*.

3.8.1.2 Participants

The participants were drawn from those who completed the online survey and indicated that they were willing to take part in the interviews. Ten hospice leaders indicated a willingness to participate and all were approached in order to generate as rich a data set as possible. Since the survey was anonymous it was difficult to ascertain the differences between those who agreed to be interviewed and those who did not. Those who agreed to participate expressed or implied either an interest in a PHAPC, support for a PHAPC or were simply being courteous.

3.8.1.3 Interviews

Each participant was telephoned by the researcher to discuss the participant information sheet and to allow time for questions or concerns to be addressed. In addition a time and date that suited the participant was diarised for the interview, and the completion of a consent form was discussed. Consent forms were emailed to the participant, signed and emailed back to myself prior to the interviews. The interviews were then carried out at the specified times, recorded and later transcribed by myself. Copies of the transcripts were emailed to each of the participants to allow them a chance to clarify or correct any of their data (member checking). Only one participant made edits to their transcript and these were minor grammatical changes.

In total, ten interviews took place over a period of two months (20 June to 2 August 2016). After the first interview the transcript was sent to the supervisor and discussed before continuing with the remaining interviews.

Telephone Interview Guide

The uptake of public health approaches by hospices in New Zealand:

Notes:

- *Thank you for agreeing to take part in this interview.*
- *A reminder that this will be audio-recorded and transcribed to assist with thematic analysis.*
- *You may withdraw your interview data or inclusion in this study up to one month from today.*
- *You may refuse to answer any question and terminate the interview at any time without giving a reason.*
- *You will be sent a transcript of this interview.*
- *Your identity and the identity of your hospice will be kept confidential.*

General

There are a growing number of voices linking public health to palliative care.

1. When you read or hear a speaker talking about a public health approach to palliative care, what do the words 'public health' bring to mind? Could you explain further?
2. What has shaped your thinking in this regard?
3. Are you in favour of this approach?
4. Do you think there are any risks with adopting this approach?

Community Engagement

The public health approach, that is the social model of health promoting palliative care, upholds community engagement as key to achieving its' goals.

5. What do you see as the aim of community engagement?
6. How would you define your local 'community'?
7. What groups are hard to reach?
8. How do you engage with hard to reach groups?
9. Do you think there are any groups of people who miss out on community engagement activities?
10. What type of community engagement activities is your hospice doing?
11. How successful do you think they have been?
12. What things do you experience as barriers to community engagement?
13. What things help facilitate community engagement?
14. How do you see your involvement with this work developing in the future?

Social network approaches

One public health approach is the social model of health promoting palliative care which aims to empower communities to care for their dying, often through the use of caring/social networks. In such a model the community leads caring work and specialist palliative care professionals act as a back-up support.

1. Are you familiar with this model? What does this model mean to you?
2. Are you in favour of this model? Why?
3. Do you think there are any problems with it?
4. What does 'empowering communities' mean to you?
5. Do you think there's a risk that certain groups of people could be excluded from this type of model?
6. Do you think this model represents a change in direction for your hospice?

Figure 3.3 Copy of interview guide

3.8.2 Data Analysis for Phase 2 – Telephone Interviews

3.8.2.1 Thematic Analysis

Thematic analysis was chosen as the method of analysis as it has been found to well-suit the type of data obtained from semi-structured interviews (Payne, 2007). This method has been described loosely as, “a method for identifying, analysing, and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 6). In particular thematic analysis, allowed me to create a descriptive account of common understandings of a PHAPC. Other methods, such as content analysis, grounded theory, narrative analysis and discourse analysis were discounted because of a poor fit with the data itself or with the aims of the research question.

Similar to the thematic analysis of the literature described in chapter two, the analysis of the interview data took place over the progressive and systematic stages suggested by Braun and Clarke (2006) and Holloway and Wheeler (2010):

- a. Data familiarisation and organisation
- b. Generating codes
- c. Developing themes

3.8.2.2 Data familiarisation and organisation:

Generating the transcripts verbatim formed the starting point of the analysis. It was the means of familiarisation with, and organisation of, the data I carried out the transcribing of each interview. This process allowed close reading, reflection and familiarisation with the raw data which was essential to gaining insight into the details as well as an overall impression of the data. Indeed, immersion and engagement with the data is recommended by Holloway and Wheeler (2010) for qualitative data analysis. In addition close reading allowed me to notice missed opportunities where I could have probed further, and identify possible gaps in the data.

The transcripts included the date, time, and relevant data taken from the survey responses, for example the hospices geographical location, services offered and whether or not they had indicated support for a PHAPC.

3.8.2.3 Generating codes:

The next step in the analysis process was coding. “A code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence –capturing, and/or evocative attribute for a portion of language based or visual data”. (Saldana, 2009, p. 3).

The transcripts of each interview were coded separately. This allowed for the coding towards as many potential themes as possible, to ensure no interesting or relevant ideas were excluded. Coding was an iterative process, with repeated rounds of refining. The initial or first round of coding used *in-vivo coding*, using the actual words of the participants. This prevents the researcher from imposing their own ideas on the text (Holloway and Wheeler, 2010). Codes were then reflected upon and further refined. The outcome of this stage of coding was the generation of descriptive codes which were statements that reflected the essence of the idea expressed. For example:

Table 3.7: The development of codes

| Transcript extract | Initial In vivo code | Refined code | Final descriptive code |
|--|-------------------------------|--|-------------------------------|
| <i>So we've done a couple of those, and invited people to come along and have the discussion about end of life etc... We didn't get huge uptake...Um, so it's interesting...So, we'll see what eventuates there.</i> | <i>Didn't get huge uptake</i> | Hesitancy due to experience of poor uptake | Limited uptake |

A code book was generated in the form of multiple excel spread sheets which listed all the descriptive codes under each section of the interview. For clarity, each code had a reference back to its' original transcript for easy cross-checking of context and meaning during the subsequent analysis.

The next step in the coding reflected the inductive nature of qualitative research, meaning that many diverse ideas were condensed into fewer, and broader, encapsulating categories. Using the codebook, the descriptive codes that reflected similar ideas were grouped together into categories and were given an analytic code. An example is shown over the page:

Table 3.8: The development of categories

| Descriptive code | Analytic code/Category |
|---------------------------------|-------------------------------|
| Wait and see. | Uncertainty |
| Wait and see. | |
| Uncertain. | |
| Willing to try. | |
| It's an option. | |
| It's one way. | |
| Hesitancy. | |
| If people want it we'll try it. | |
| Reluctance. | |
| Possibly in the future. | |
| Limited uptake. | |

Some descriptive codes fit into more than category, which according to Braun and Clarke is acceptable (2006). For example the descriptive code ‘compassionate communities are about resilience in the community’ was allocated to two categories, those being ‘community’ and ‘changes in thinking’, as it reflected the ideas of both.

3.8.2.4 Developing themes:

The development of themes was the final step in the analysis of the data. A theme is a phrase summarising the subtle or implicit idea linked to a set of resonating codes (Saldana, 2009). This generating of themes relies on the insight and interpretation of the researcher. According to Braun and Clarke (2006) the active role of the researcher in generating these themes is to be acknowledged and embraced.

Following this logic, the categories were then intentionally and intuitively grouped into sub-themes. These groupings were done with frequent cross checking back to the original meanings in the transcripts. This constant checking back to the transcript was to prevent the researcher from making inaccurate inferences and reaching premature conclusions - a danger Holloway and Wheeler caution against (2010).

Once I had allocated all the categories into sub-themes, I regrouped them again into fewer potential themes. Braun and Clarke (2006) suggest that a thematic analysis of data for a master’s project should yield between two and six themes depending on the length or word-count of the work. A table was developed to summarise the categories within each sub-theme and theme. This table provided a useful overview of the groupings and assisted further refining and was checked and approved by the research supervisor during the refining process. The final table is presented with the study findings in chapter four. An earlier version of

this table includes a count of the codes, and a map tracking the development of categories, sub-themes and themes, may be found in Appendix 7.

In naming the sub-themes and themes, I was cautious to avoid simply taking the headings from the different sections of interview schedule and making those the themes. Braun and Clarke (2006) urge the need for the themes to reflect analysis and not simply a re-telling of the questions. Therefore I kept asking myself, “What is the meaning of this sub-theme or theme?” A full description of the final themes is found in the next chapter detailing the results.

3.9 CONCLUSION

This chapter has described the philosophy or methodology underpinning this study. It has also described in detail the methods used for data collection and analysis in each phase of this mixed method study exploring the uptake, nature and understandings of a PHAPC by hospice in New Zealand.

CHAPTER FOUR: RESULTS

4.1 Introduction

Using the methodology and methods outlined in the previous chapter, a mixed method study exploring the status of a public health approach to palliative care (PHAPC) in hospices in New Zealand was carried out. This chapter will present the findings from this study. The quantitative results from the online survey of hospice leaders will be presented first, followed by the qualitative results from the telephone interviews with a sub-set of the same group. Finally both sets of results will be triangulated to consider commonalities and differences.

4.2 Preface to the findings

Given the small number of hospices in New Zealand, and the close-knit nature of this group, careful attention has been given to the wording of the results so that inadvertent identification of a hospice or the hospice leader does not occur. No identifying features (such as location, or hospice size, or specific services offered, or position of leadership, or gender) are linked to individual responses in the presentation of these results. Each leader that completed the survey and then took part in the interviews was allocated a number between 1 and 15, and these numbers are used to reference any quotations. Quotations were carefully selected and checked to ensure that the context fully supported the idea being demonstrated.

4.3 Quantitative results

The following findings are those generated from an online survey of hospice leaders. The same survey tool was administered to palliative care services in the UK in 2013 (Paul & Sallnow) and was adapted with permission for use in New Zealand. It was a simple scoping survey with seven questions. Analysis of the data was limited to descriptive statistics due to the anonymous nature of the survey and the sample size both limiting the number of variables for multivariate analysis and inferential statistics.

4.3.1 Response rate

The sample selected for the online survey was a whole population sample i.e. the whole population of hospices in New Zealand. It was anticipated that such an inclusive sample would facilitate the generalisability of results from the quantitative data. Out of 28 hospices eligible to participate, 15 took part in the online survey, representing a response rate of 54%. Baruch (1999) conducted a comparative analysis of response rates in academic literature. This analysis found that surveys of people in top management positions, such as CEO's, typically yield lower response rates than surveys of other populations. The same study found that the norm for this group of respondents was 36% and recommended that studies should aim for within one standard deviation of this score. The response rate for this study is therefore well above

Baruch's (1999) recommendation. It should also be taken into account that online surveys typically yield lower responses than traditional surveys (Flick, 2011). In fact SurveyGizmo state that internal online surveys usually attain a response rate of 30-40%, while external surveys achieve only 10-15% (Fryrear, 2015). Therefore, a response rate of 54% in this instance is thought to be good.

4.3.2 Participant and hospice characteristics

Of the survey participants 60% were female, 20% were male and 20% did not give their gender. In terms of their leadership roles at their respective hospices, 60% were the Chief Executive Officer (CEO), 20% held other positions of leadership (these were nominated by their CEO's to participate on their behalf) and 20% opted not to specify their leadership roles. No other demographic information regarding the respondents was collected.

Table 4.1: Characteristics of the survey respondents

| | CEO | Other position of leadership | Unknown | Total |
|---------|-----|------------------------------|---------|-------|
| Male | 2 | 1 | | 3 |
| Female | 7 | 2 | | 9 |
| Unknown | | | 3 | 3 |
| Total | 9 | 3 | 3 | 15 |

The majority (80%) of hospices represented were from the North Island and 20% were from the South Island. This is reflective of the distribution of hospices across New Zealand, as there are more hospices in the North Island. The bulk of hospices (69%) served a mixed population working in both rural and urban settings. With the exception of one, all of the hospices represented in the survey provided home care in the community.

Table 4.2: Characteristics of the hospices

| | Number of responses | Rural population | Urban population | Rural & Urban population | In-patient service | Home care Service | Day Hospice service |
|------------------------------|---------------------|------------------|------------------|--------------------------|--------------------|-------------------|---------------------|
| Hospices in the North Island | 12 | 2 | 3 | 7 | 10 | 12 | 9 |
| Hospice in the South Island | 3 | 0 | 0 | 3 | 2 | 2 | 1 |
| Total | 15 | 2 | 3 | 10 | 12 | 14 | 10 |

4.3.3 Survey Findings

The quantitative findings from the survey will now be presented according to the two main aims of the survey. These are firstly the uptake of a PHAPC and secondly the nature of a PHAPC.

4.3.3.1 Uptake of a public health approach to palliative care

The survey results demonstrate significant support for a PHAPC by hospice leaders in New Zealand. When asked if this approach was a current priority at their hospice, 60% (n=9) of those leaders surveyed responded that it was. A further 33% (n=5) said that although it was not a current priority, it was likely to become one in the future. One respondent selected the option stating that it was not a priority due to a lack of resources. No leaders selected the option that stated that a PHAPC was not within their remit.

This uptake is demonstrated by activities reportedly carried out at the hospices. These activities, selected from a given list, typically reflect a PHAPC and more specifically community engagement. All activities were related to loss, death, dying and/or hospice care.

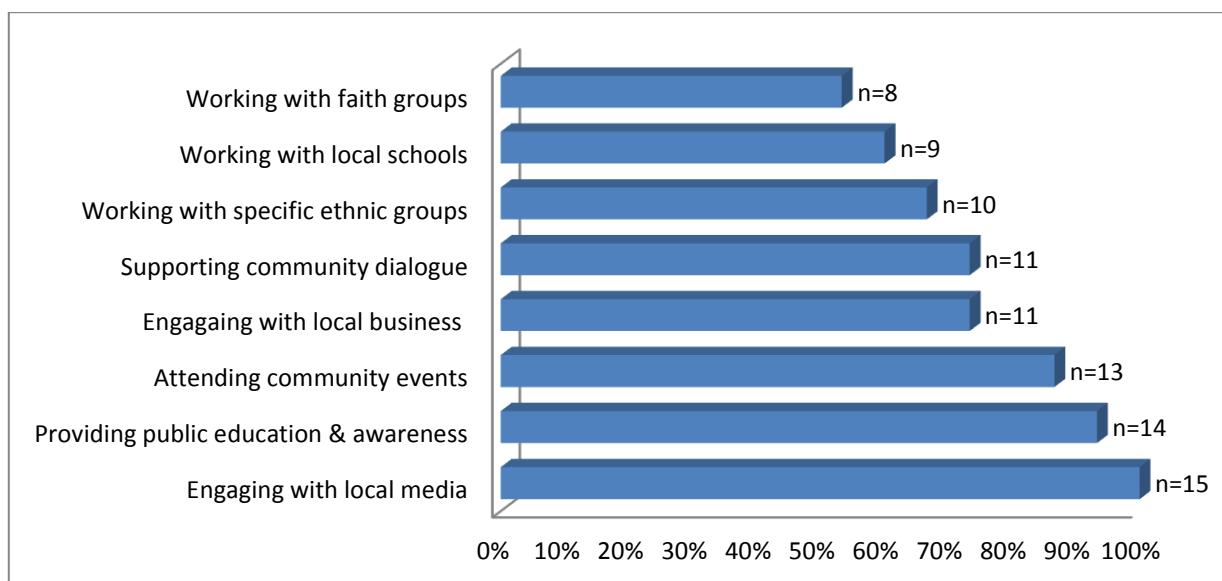


Figure 4.1: Bar chart showing the percentage of hospices carrying out selected community engagement activities

4.3.3.2 Nature of a public health approach to palliative care

While the activities reported above might superficially be thought to be community engagement, the true nature of the activities is more clearly demonstrated when the respondents were asked to describe them in greater detail. As discussed fully in chapter three, a content analysis method (Payne, 2007) was used to categorise and count frequencies of predetermined codes. Activities were categorised according to the

spectrum of community engagement (Sallnow & Paul, 2014). This spectrum, also discussed in chapter three, depicts less powerful community engagement on the left and more powerful community engagement on the right, and gives guidelines on how activities might be positioned on the spectrum according to their aim and focus.

During this analysis, of the 55 activities described, 87% ($n=48$) were classified as falling at the weaker end of the community engagement spectrum; in other words the aim of most of the activities was to *inform* or *consult* with the community. A further 12.7% ($n=7$) of the activities were classed as being a *co-production*. No activities could be classed as being *collaborating* or *empowering*.

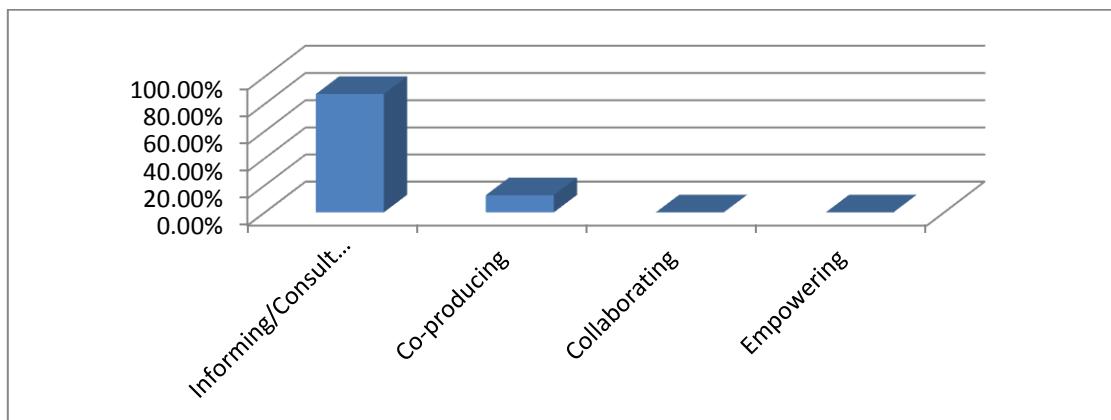


Figure 4.2: Graph showing the percentage of activities allocated to points on the community engagement spectrum

Hospice leaders were also asked from the same list of activities to identify those activities they had found to be most successful. From the list of eight activities, a collective total of 36 items was selected by the leaders. Their selections are shown below.

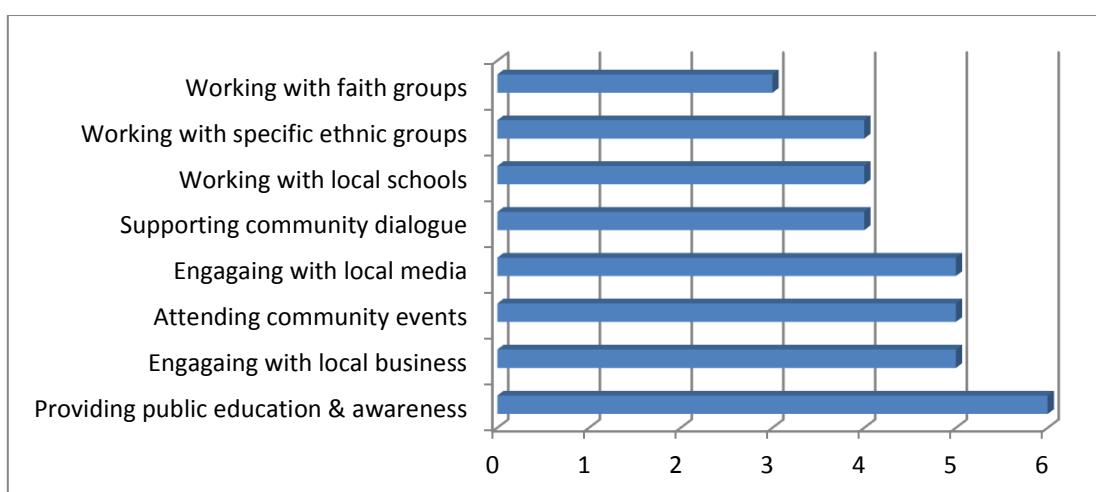


Figure 4.3: Bar chart showing the distribution of community engagement activities selected as most successful by the hospice leaders

The leaders were then asked to explain why they felt these activities were the most successful, and 14 of them provided answers. Again the content analysis method was used to allocate data to pre-determined categories using pre-determined criteria. True community engagement aims to benefit the community (Sallnow & Paul, 2014). Only 14.2% (n=2) of these leaders spoke about these activities as benefitting the wider community in some way; that is benefitting people beyond patients and families. Another 14.2% spoke about the outcomes as being mutually beneficial (n=2). Conversely, 35.7% (n=5) of the leaders noted the main reasons for selecting these community engagement type activities was because they were beneficial to the hospice service. Another five leaders did not state reasons for their selection of activities.

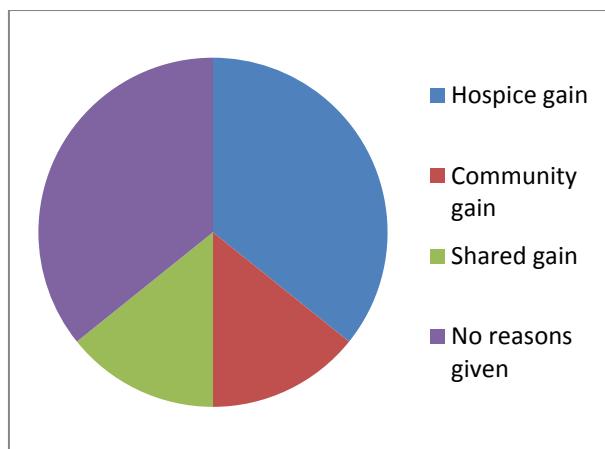


Figure 4.4: Pie chart showing the perceptions of gain related to community engagement activities

Finally the survey afforded respondents the opportunity to write their own comments on the role of hospices in relation to PHAPC. Twelve respondents gave short answers to this final survey question.

Six respondents spoke about their commitment to a PHAPC and showed insight into the approach by using terms such as health promotion, community resilience, and community capacity, community empowering and population-based ideas. Many of these also included comments about core service provision and education.

Three respondents spoke of a PHAPC solely in terms of service provision, mentioning patients, whānau and education services.

Two respondents spoke about the perceived cost of a PHAPC as being a barrier:

Have looked at the ‘compassionate communities’ work in the UK and feel we need to follow suit here in NZ. Having staff resources to facilitate is our issue.

#1

We are feeling our way here and trying to think about how we can fund this as a sustainable service.

#9

4.4 Qualitative Results

The aim of the semi-structured interviews was to further explore the nature of a PHAPC at New Zealand hospices and hospice leader's understandings of the approach. The findings from these interviews add depth to the quantitative findings which focussed on the uptake and nature of the approach. Of the 15 hospice leaders that responded to the online survey, 12 of these indicated that they would be interested in taking part in further telephone interviews, and of these 10 were able to participate within the time frames required and were duly interviewed. Eight of those interviewed were the CEO at their hospice, and two were senior managers on leadership team at their hospice. The inability to comment on the differences between responders and non-responders is discussed in chapter three (3.8.1.2).

Table 4.3: Characteristics of the interview participants

| | CEO | Other position of leadership | Total |
|--------|-----|------------------------------|-------|
| Male | 2 | 1 | 3 |
| Female | 6 | 1 | 7 |
| Total | 8 | 2 | 10 |

Using thematic analysis, the transcripts of each interview were coded and themed as detailed in chapter three. This process involved grouping the descriptive codes into analytic codes or categories. The categories were again grouped into nine sub-themes and finally into four overarching themes. The final four themes were *Taking stock: current understandings of a PHAPC*, *Growing community engagement*, *New tools* and *Recalibrating palliative care*. Table 4.4 summarises the allocation of categories, sub-themes and themes.

Table 4.4: Summary of codes, categories and themes

| Analytic codes/categories | Sub-themes | Themes |
|-------------------------------------|--|--|
| Internal influences | Prompts | Taking stock - current understandings of a PHAPC |
| External influences | | |
| Community | Popular elements | |
| Population perspective | | |
| Education | | |
| Health promotion | | |
| Definitions | Descriptions of community | Growing community engagement |
| Hard-to-reach groups | | |
| Low level community engagement | Community engagement skewed to the left | |
| High level community engagement | | |
| Barriers | Influencing factors | |
| Enablers | | |
| Awareness | Limited formal knowledge of a social network model | New tools |
| Support | | |
| Social isolation as a challenge | | |
| Other challenges | | |
| Support | Death café uncertainty | |
| Uncertainty | | |
| Changes in thinking | Changes and challenges that a PHAPC brings | Recalibrating palliative care |
| Challenges | | |
| Support | | |
| Medical model of death | Contemplating models | |
| Specialist model of palliative care | | |

The four overarching themes relate to the current understandings of a PHAPC, which is a relatively new approach to palliative care, by hospice leaders in New Zealand. In brief these are:

i. Taking stock: current understandings of a PHAPC.

The features commonly associated with a PHAPC by hospice leaders were a focus on community, health promotion, education and a population perspective. While their own work and study experiences had shaped these understandings, the influence of organisations such as HNZ, the compassionate communities' movement in the UK and well-known academics such as Allan Kellehear were also reported as having been influential.

ii. Growing community engagement

Community engagement, one of the key methods of a PHAPC, and seen by some as a synonym for a PHAPC, is something all the leaders felt they were doing. Community was most commonly described in terms of people that were linked to the hospice service in some way. Most leaders identified that ethnic minority groups were the hardest to reach with regards engaging the community. The community engagement activities described tended to be those on the inform-consult end of the community engagement spectrum. The hospice leaders identified a number of barriers and facilitators to community engagement.

iii. New tools

Death cafes and the use of social networking are two new ideas related to a PHAPC. Among the hospice leader's formal knowledge of the social network model was found to be relatively low, although there was good support for the concept and a number felt they were already applying the principles of the model. Among other things, social isolation was seen as a significant barrier to mobilising social networks for support. There was marked ambivalence about the death café concept, and most leaders were uncertain of the value of them.

iv. Recalibrating palliative care

Data allocated to this theme relates to some of the shifts and challenges that a PHAPC brings. In particular this theme highlights the existing contemplation of the medical and specialist models that currently dominate palliative care.

Each of these four main themes will now be presented in greater detail.

4.4.1 Theme 1 - Taking stock: current understandings of a PHAPC

Data generated from interviews with hospice leaders were used to establish what current understandings of a PHAPC were among hospice leaders. Two sub-themes contribute towards this theme; these are *popular elements* and *prompts for the approach*. These subthemes respectively reflect those elements commonly associated with the approach and the influences that shaped understandings of the approach.

4.4.1.1 Sub-theme 1: Popular elements

When asked what came to mind when they heard the term ‘a PHAPC’, there were four features that hospice leaders commonly associated with this approach. These were education, community, a population perspective and health promotion.

Education was the element most commonly associated with a PHAPC. While education for patients was mentioned by one leader, and education for health care workers was mentioned by another, the remainder of the discussion was about education for the public. Most of the references to educating or informing the public were addressing the perceived need to improve awareness of hospice and palliative care. One leader raised the concern that the messages around a PHAPC were complicated, and the language too technical, and this in itself was a challenge to educating the public.

Yeah, getting it out into the open, with the public, and increasing awareness really.

#1

Mention the word ‘hospice’ and it generates this image of a building where people go for a couple of days to die. We’ve been trying to explain to the public, well for as long as I’ve been involved in hospice, that it’s actually more than that – it’s a whole philosophy of care. Um, and you know I go back to the same sorts of groups, retiree groups and things like that, time and time again.

#13

Community was also recognised as an integral part of a PHAPC. While a couple of leaders referred to the community merely as the place where services should be delivered in geographical terms, most spoke of the community in terms of people and partnerships. There was recognition that a PHAPC is a social model with the aim of building resilience in the community. The role and responsibility of the community in the provision of care was also mentioned. One leader highlighted the contribution that community organisations make towards the provision of care and support.

It’s a much broader social issue, and it acknowledges how communities do most of the work in supporting patients in their families and their carers. When you know someone is dying and in that loss and bereavement time and that services are just a relatively small part of the whole picture. And that it’s not just about hospice and palliative care services, it’s very much around whole communities.

#8

I guess what immediately comes to mind is what organisations are involved in public health, and I think more of what’s in the community. And that could be a number of private health clinics, whatever.

#14

Another element associated with a PHAPC by three leaders was a **population perspective**. While two of these did not make clear what exactly constituted a 'population', one leader did refer to their clients as their population, in other words the patients and families.

Um, a public health approach is a population-based approach; it's looking at the whole population needs, and thinking about all components of that community.

#11

And we ultimately closed down (a programme) because it wasn't serving the needs of our population...What we believed was that our patients and families would benefit more from a structured education programme to enable them to manage those sorts of things that they find tricky at home at end of life.

#2

Lastly **health promotion** was connected to a PHAPC by two leaders. Only one of these explained their understanding of health promotion, linking it with self-management.

I guess I start thinking about health promotion, and I think about a self-management approach.

#2

You know when I think about it, it may even go as far as the stopping smoking campaigns or whatever. It's about improving health in general so that we have a healthier population by the time they come to palliative care.

#6

4.4.1.2 Sub-theme 2: Prompts for the approach

The self-reported influences on leaders thinking and understandings of a PHAPC were identified as being either internal or external influences.

Internal influences are those triggers initiated by the leaders themselves. Three of the hospice leaders interviewed reported that their own reading and study had shaped their thinking. Two leaders said that their own experience working in the public health sector, had influenced their understandings of the approach.

I'd done quite a bit of reading...

#8

You know there's nothing that shapes how you feel about a subject more than actually having experiences at the coal face. So when I look back on my career...I had experience... working in public health.

#14

External influences were reported by the other five leaders as having the greatest impact on their understandings of a PHAPC. One leader reported that working with local bodies such as the district health board and national bodies such as Hospice New Zealand had informed their understanding of a PHAPC. One said that the compassionate communities' movement in the UK had had a big influence on them. Three leaders mentioned the important influence of individual scholars whom they had heard speaking at conferences or who had come to know more closely through hospice work. In particular Allan Kellehear, Joachim Cohen and Richard Eagan were identified as being influential. One leader also spoke about the impact that an allied health professional at their hospice had made on their understandings of a PHAPC and in particular of well-being at the end-of-life.

Yeah, Allan Kellehear, reading his work and meeting him, and listening to him speak, that sort of, you know he was probably the early proponent of a public health approach. And then more recently Joachim Cohen, yeah. So they've probably been influential.

#11

4.4.2 Theme 2 - Growing community engagement

This theme describes current understandings of community engagement among hospice leaders. Community engagement is an important component of a PHAPC, and even seen by some as another term for a PHAPC. All those interviewed felt they were doing community engagement, and recognised the growing importance thereof. Data from three sub-themes, namely *descriptions of community, community engagement skewed to the left* and *influencing factors* all contributed to the establishment of this theme.

4.4.2.1 Sub-theme 1 Descriptions of community

Community is a broad term and not surprisingly the participants defined it in different ways. They also identified those groups that they felt were particularly difficult to engage with within their communities.

In terms of **defining community**, the leaders described the term in dissimilar ways. One way in which community was defined was in terms of people. Most of the leader's defined community as those people touched in some way by the hospice service, and two of these leaders specified these to be patients and families. Other local health service providers were also included in one leader's definition of community. The community as being various groups that required educating about the hospice, and the community as a

potential workforce were two other perceptions. Only three leaders had a wider view of community that included the public more generally.

The community around the hospice tend to be those that have been touched by the hospice.

#12

Well when we define community, it's very much in its broadest sense. So the community we serve as a hospice. So don't think about just the patients and families and whānau, on our books, it's much broader than that. It's the community within which – so the individuals and families and whānau, NGO's – all those kinds of things, as well as our business community who support us in different ways as well.

#8

Another way community was described was with reference to places. Data from three leaders defined community in terms of geographical places or boundaries. Local infrastructure was included in one leaders description of the region they considered their community.

A community is where people live and work.

#5

Three leaders included elements of both places and people in their explanations of community.

We are everyone that lives within the (name of region).

#6

I talk about everybody out there; in our case in (name of region). Man, woman and child.

#1

Leaders were asked directly to identify the **hard-to-reach groups** in their own communities in terms of them being challenging to engage with. The majority of leaders responded that within their communities ethnic minority groups were the hardest to engage with. Māori and Pacifica in particular were identified as being difficult to engage with, while Asians and Philippinos were also mentioned. Other groups that were identified as being hard to reach were younger people and the primary health sector. One participant felt that instead of focussing on hard-to-reach groups, they should be targeting groups that have potential to impact and influence the wider community on matters related to death and dying. Groups with such potential were thought to be schools, churches, sport clubs, councils, the army, and academic institutions.

I would say mostly, people would be in agreement here, that the hard-to-reach group are the Māori and Pacific Islanders.

#14

You know, younger people, it's not really on their agenda, and it's something that becomes more in focus I guess as you get older...that's human nature, you know, when you're younger you're bullet proof, you're going to live forever so to speak, so you're not thinking too much about those sorts of things.

#1

4.4.2.2 Sub-theme 2 Community engagement skewed to the left

The leaders' views and comments on community engagement could be assigned into two broad categories, depending on the descriptions given. One captured perceptions reflecting less powerful levels of community engagement (the left of the spectrum), and other category those reflecting more powerful levels of community engagement (the right of the spectrum). The spectrum of community engagement and the rationale of how activities might be placed on the spectrum has been explained in chapter 3.

Activities on the left of the spectrum are considered less able to bring about lasting health and social changes than those on the right of the spectrum because they tend to involve less community participation (Sallnow & Paul, 2014). Most of the data from participant's views and descriptions of what they called community engagement was focussed on service provision, on patients and families, and on the community merely as a place of work. Therefore this data demonstrated **less powerful community engagement**. For the most part, accounts of community engagement revolved around *social marketing* of the hospice service. Activities mentioned included doing awareness talks at social clubs, and having a hospice presence at public events. Leaders used the words such as 'awareness' and 'promotion' in their discussions of community engagement. The goal of such activities was identified as being to increase awareness of the service, to improve understanding of the service, to improve uptake of the service, and to raise the public profile of the service.

We do awareness programmes, whether they be around going out and speaking to other health care providers, or speaking to interested groups like Probus. And you know all of those community groups that we speak to; again you're engaging them in a concept (hospice).

#14

We do promotion of our services at events - we might have stalls, shops, radio advertising. It's usually advertising the shop or advertising hospice in general.

#5

Recruiting and working with volunteers to provide services was also labelled as community engagement. Volunteers were recognised as members of the community, with influence in the community, and therefore engaging with them was considered the same as engaging with the community. Data related to volunteers in this context was linked to the provision of services to patients and families, and not in the context of equipping the volunteers themselves or the wider community with skills around death and dying.

Community engagement is also important in the provision of getting volunteers.

#6

We've just taken someone on who, because we're trying to look to the future, (they are) going to recruit and manage volunteers...I feel really excited about that, because I think it's going to hugely powerful...growing the volunteer base and the community support base for the patients.

#11

Fundraising activities were also associated with community engagement. Four leaders explicitly stated that generating financial support was the aim of community engagement.

Fundraising. You know it's always usually about fundraising.

#5

And then it (community engagement) also raises awareness and funds.

#2

Education of both patients and their families as well as the training of health care workers in palliative care was also linked with community engagement in that both groups were being equipped. The patients and families were equipped to cope better while the health workers were equipped to provide better care of palliative patients. Again, in both instances the ultimate focus is providing care and support for patients and families.

It educates about what it is that we do, and um what's available to the community. So, the other providers of health services – that's one community we are confidently educating...and then I guess the other community is the patients and families.

#2

Five leaders raised the idea of partnerships when talking about community engagement. However the context of their descriptions of partnerships was consistently related to the provision of services. Two mentioned consulting the community during projects to develop their services further. Another spoke of consulting the community simply to hear what their thoughts and needs were. Engagement was described by one as the hospice and the community sharing resources in order to provide better services. Still another

spoke of engaging community partners in order to achieve mutually beneficial outcomes for service delivery. One leader used the stronger term of 'collaboration' when talking about community engagement but again this was regarding service development and provision.

We have also collaborated with (another service provider) here in (town) recently to do a couple of bereavement programmes...

#14

It was a great opportunity to surround us with stakeholders, all the way from health care practitioners through all the disciplines, through to community and patients and the like, and that was actually a really interesting process for us. I mean we learnt a lot, we listened a lot, and there are lots of things that they would like...And we also made new contacts and new partnerships through it. So those sorts of things are great opportunities for health care.

#13

Empowering was defined in a variety of ways, but again, all could be related in some way to the provision of care or services. One leader mentioned empowering people to care for themselves; another mentioned empowering volunteers to provide care. Empowering was also associated with saving money for the public, with the provision of education, and with working in the community. The hospice model was described by one leader as an empowering model. Another thought that giving people options for their care was empowering.

What we strive to do here is empower and enable people...We want them to be able to do for themselves.

#14

Well one part of it, is save some tax payers money.

#1

The second category within this theme was labelled **more powerful community engagement**. The activities described had a bigger focus on working with the wider community, with the goal of increasing the capacity of the community. Participation and community benefit are the intentional aims of such activities. It is precisely these aims that distinguishes the data allocated to this category, and what makes them more powerful. Considerably less data was allocated to this category compared to the first category.

When talking about community engagement, one of the repeated ideas was *partnerships* with the community. The distinctive element of the partnerships spoken of in this second category is that they were not explicitly associated with benefits to the hospice service. Instead sharing responsibility and ownership, particularly for decision-making was seen to be important. It was highlighted by one leader that partnerships meant allowing all partners equal voice, and another mentioned power sharing as an important aspect of

community engagement. Participation and trust were mentioned as important values in partnering with people. One leader said that community engagement was about doing things with rather than to people.

The aim of community engagement would be bringing all parties to the table and giving everybody an equal voice.

#4

I suppose the aim of community engagement for me is to develop trust between parties.

#13

In this category where data reflected more powerful community engagement, hospice leaders spoke about equipping the wider public, beyond just patients and families. Equipping was thought to be achieved through promoting advance care planning and through education activities. The aim of community engagement was described as increasing community resilience and equipping the wider community with caring skills.

Breaking down barriers related to death and dying was also related to equipping the wider public.

It's about making that more resilient community – having that training.

#6

And we make a lot of our education programmes...whether it be on diets in cancer or whatever it might be, physiotherapy or whatever it is, open to the public. So our community can come along to that.

#14

Similarly, when asked to share their understanding of empowering, two leaders related their answers to the wider public. One said that it meant enhancing resilience in the community. Another, using Advance Care Planning as an example, described how empowering might mean encouraging the community to be more involved and to be more directive regarding end of life issues.

And maybe, like advance care planning, if that was taken up by community groups, you know 'this is right for us and we should be doing this', that would be so powerful rather than professional groups saying 'you need to be doing this'.

#12

I think empowering communities is around enhancing – it's all about enhancing community resilience, so people feel better prepared across all realms to cope with death and dying and grief and loss.

#8

Three leaders showed insight into the complexities of community engagement by identifying that there are different levels of activities, and that these activities sit on a continuum of community engagement.

And I guess you know there's that continuum.

#8

Well in my role here, I see it (community engagement) as really multi-level.

#14

4.4.2.3 Sub-theme 3 Influencing factors

In the interviews, the hospice leaders identified a number of barriers and enablers of community engagement. These influencing factors are now discussed.

Most of the identified **barriers** were operational-type obstacles that were varied in nature. Resources were mentioned by three leaders as being a hindrance to community engagement. Challenges related to culture were also raised, for example a lack of appreciation of cultural differences was viewed as a barrier to engagement. The chosen approach to community engagement was thought to be important, in particular over-complicating it, procrastinating starting and not having a systematic plan were all mentioned as barriers. Simply having other priorities was seen as an obstacle.

As much as we'd like to do a whole lot of stuff, we just don't have the money, the staff. And so when you're working with limited resources, you know, we can't do as much as we would like to do; we're too busy trying to meet our current need of providing the specialist end care part of the role.

#6

I would say that what we probably don't do, is that we don't have a strategic approach at this point...but we would have a variable approach...probably based upon whoever gives a particular engagement talk...Do we have a systematic plan, no we don't.

#12

Also related to hospice barriers were conceptual difficulties for those working in palliative care. One leader said there was a danger that a PHAPC and community engagement principles were difficult to understand for hospice workers and that this was a barrier. Possible perceptions by hospices that the aim of engagement was to shift costs back to the community was given as another hindrance. Another leader said that superficial consultation with the community was a barrier to true community engagement.

It's still a concept that is foreign for many of our staff...So what we're trying to do is...talking much more to staff, you know, 'this is how this (initiative) supports that (public health) approach', so that people can be enabled to understand it through examples.

#8

I think a potential barrier too, is that you have to be careful when we talk about this concept, is that people don't just regard this as cost-shifting things that hospice should do in our community. You know that actually the philosophy, you know, that guides us is not about doing that, but it could be perceived as such, not only by community members, but it could also be perceived as such by funding bodies, and that's not what it's about.

#8

Consultation has become overused to be a mechanism of, you know, slip it by people, and it's not actually being used to form good policy or good outcome.

#13

Public insight and attitudes towards death and dying were raised as barriers to community engagement. In particular death denial, stoic attitudes and stigma around asking for help were hurdles for engaging. Misconceptions about hospice were also noted as barriers.

The perceptions out there, you know, the myths that hospice is a place where people go to die, and it's for old people, and it's for people with cancer.

#2

The stoic attitude of people thinking they have to go it alone basically has been a barrier.

#4

Hospice leaders also felt that the health system posed challenges for community engagement. In particular funding contracts with DHB's were seen as restricting some of the engagement activities hospices would like to be involved in, but could not necessarily measure or report against. Systemic paternalism on the part of health professionals was raised by two leaders as a barrier to developing a community engagement approach to end of life care.

I think another challenge, um within that (related to funding) as well, will be that it's not an easy concept to measure necessarily the effectiveness of.

#8

Yes (the service is overseen by the District Health Board). That's the contract. And so we don't go out into homes at the current time. (Interviewer asks: So you feel you're constraint by your contract?). Yes. Yes, we are.

#5

Right from the beginning when we first organised workshops to bring people together, we were told that they (the health care professionals) were the experts and we didn't know what we were talking about, so leave it alone.

#4

A number of **enablers** were identified as facilitating community engagement. Two leaders said that being pro-active about engaging with communities was vital ingredient for success. Having a good reputation in the community was also mentioned as facilitator of engagement. In terms of engaging with various ethnic groups, one leader said that having a staff that reflected the ethnic make-up of the local community was a powerful enabler for community engagement, and opened up opportunities.

I have found that the best way to engage with those communities (Māori and Pasifika) is through their own people, and especially their own people being on your staff. It's very hard for a person from another culture to truly engage.

#11

The use of newsletters to promote awareness of end-of-life issues was seen as useful. Other more innovative facilitators of reaching out to the community were the use of the arts and drama, the use of humour, social media opportunities and the potential of using hospice shops to engage with the community. The space around bereavement was identified by one leader as an opportunity to engage.

Why aren't we thinking in this way? In terms of how bereavement might affect our communities and how we could then influence the bigger picture, the whole death and dying thing, through that.

#12

4.4.3 Theme 3 – New tools

Employing social network models as a means of empowering communities, and the use of death cafes to facilitate conversations with the community, are concepts both strongly associated with a PHAPC, and both new to traditional palliative care. These two concepts form the sub-themes within this theme, and data generated from the interviews with hospice leaders reflects their insights and understandings of these new ideas.

4.4.3.1 Sub-theme 1 Limited formal knowledge of a social network model

The use of social networks involves identifying and mobilising people's natural social supports (Abel et al., 2013; Abel, Bowra, Walter & Howarth, 2011). Involving these informal networks in the care of the dying is argued to not only empower them with skills and knowledge around death and dying, but also to help provide care and support particularly for those dying at home and their primary carers (Noonan et al., 2016; Horsfall et al., 2012).

Formal **awareness** of a social network type model was relatively low. Five of the leaders explicitly stated that they had no formal knowledge of the model and had not heard about it before. Another four leaders incorrectly described the model and therefore also displayed limited knowledge. One saw social networks as something to be created rather than something already existing, another thought it may have something to do with social media, another thought it meant compassionate communities, and another thought it involved the use of volunteers.

(Question: Have you heard about this model?) Not really, no, no.

#5

(Question: Have you heard about this model?) No I haven't. It sounds intriguing.

#11

Our volunteer list is just - I mean the capability that's come forward is just incredible. And it's just amazing to put these really useful people to work and have them supporting others.

#4

Only two leaders were aware of social network models, and described it correctly in terms of identifying and mobilising existing social supports.

And a key part of their role is to identify both the informal and the formal networks that are around a person, and how do they mobilise those.

#8

Despite limited formal knowledge of a social network model, there was significant **support** among hospice leaders for the concept. Four leaders felt that they were already applying elements of this model at their hospices. Three leaders expressly supported the concept when it was explained to them. Two leaders felt

that the tasks of identifying and mobilising social networks should be incorporated into existing roles, and not made into a distinct job description requiring additional staff.

I haven't heard about that model, but actually that's something that we do as a matter of course here.

#6

Social isolation was identified as a challenge to applying a social network model. Eight leaders agreed that this was a significant and growing issue within their communities. All of these eight leaders highlighted older people as a specific group of people that suffer from social isolation. Four leaders expressed doubts over the appropriateness of hospices in providing support to isolated older people with no palliative needs. One leader said hospices were ageist and needed to broaden referral criteria in order to support older people who by virtue of their age are nearing the end of life and therefore do have palliative needs. One leader said social isolation among the elderly was not a hospice priority, another said there were already support services in place for older people, another said that this kind of support was the responsibility of the state and not hospices, and another said that hospices did not have the resources to address this need.

So it was quite a debate about whether that was appropriate. (Referencing using hospice volunteers to provide companionship to a lonely resident in aged care).

#4

For hospice, one thing that really, I think we have to go back and look at our referral criteria because I think that we are quite ageist, and I often think well, okay, this person may not need specialist palliative care, but they need a whole lot of other things that hospice can provide, like volunteers.

#11

One participant observed that older people are not the only ones that might suffer from social isolation, and that indeed family carers and people from some immigrant cultures might also be at risk.

Carers as a group often become socially isolated, you know they, for lots of different reasons don't link up with their friends and neighbours and groups they've been associated with for whatever reasons, and try to go it alone.

#8

A further five **other challenges** were collectively raised regarding applying a social network model.

Diminishing networks due to smaller families or distant families, living in a rural location, and limited technical savvy were thought to be challenges for successfully mobilising social networks. It was also thought to be difficult to maintain confidentiality while at the same time identifying needs and mobilising community solutions. Lastly paternalism on the part of palliative care and other health professionals was also identified as a challenge to recognising the resources and skills existing in social circles or networks.

If we could have our district socially networked with a benign strong network affiliation that is aware of when palliative needs strike or when aged care needs strike, that they can assist in linking people to the right aspects of care for them, and to link to community support networks together in an appropriate way. Again it's about choice, isn't it? It's about pick-up or take-up, rather than being paternalistic around provision.

#11

4.4.3.2 Sub-theme 2 Death cafe uncertainty

Death cafes are a means of facilitating informal discussions around anything to do with death and dying.

Many organisations involved in end-of-life care that support a PHAPC have undertaken these as a means of engaging the wider community in conversations, as one way of beginning to overcome death denying attitudes. When hospice leaders were asked to reflect on death cafes, it was evident that most of them were somewhat cautious about the concept.

Three leaders expressed their **support** for the idea, and two had organised death cafés in their communities. They felt them to be worthwhile, and useful in breaking down barriers to having conversations about issues related to death and dying.

We would look to introduce something like that at some stage...that's definitely something that appeals to our counsellor to get started up. We definitely appreciate that we need to get people to talk about death more, to break down some of those barriers.

#4

However, most of the interview data reflected **uncertainty** about death cafes. The majority of hospice leaders felt uncertain about the value of death cafes. Four leaders expressed a dislike of the terminology 'death cafe', and one said the name may even be a barrier to conversation. One leader said they had tried it and had limited attendance. Another said they might try one at a later date but not now. Another four were

reluctant, saying that death cafes were not the best option, but that they were willing to try them if that was what people wanted. Two leaders felt they would wait and see if the idea had success elsewhere.

I'm supportive of the idea but we were reluctant to call them death cafes and I think that while that may be okay – that terminology with some people, I think it could actually be a barrier to some people participating too.

#1

Hate the name. That's a personal thing....I find it an interesting concept...I'm not sure that death cafes are the answer. They might be part of the answer, you know?

#14

I don't know why but I'm not a huge fan...what I hear is that ...the people who come are the converted...I'm not sure that that's the very best way.

#11

But we didn't go to the death café idea. We know it's there, people have talked about it. Not sure if we're going to be serious about that one or not.

#12

4.4.4 Theme 4 – Recalibrating palliative care

Adopting a PHAPC necessitates a shift in thinking and practice for those working in palliative care towards a more social model of end of life care. Hospice leaders spoke about the potential changes and challenges that such a re-orientation might pose. They also reflected on their support for the movement going forward. There was considerable contemplation on specialist and medical models of care, a discussion that this social model has put the spotlight on.

4.4.4.1 Sub-theme 1 Changes and challenges that a PHAPC brings

Participants felt that a PHAPC required some **changes in thinking**. Three hospice leaders identified that a PHAPC could require palliative care to consider wider admission criteria, and not to focus only on the end of life. Two leaders spoke of a requirement for earlier interventions to prepare people for death and dying. Similarly, building earlier relationships with people was seen to as key. The need for death to be genuinely conceptualised as a part of well-being was thought to be important.

It's just generally that acknowledgement that palliative care is not just about end of life care.

#1

Any public health approach to palliative care, is when you're trying to introduce the public to new approaches...so that they're prepared for something to happen in the future, getting ahead of the game, being prepared.

#13

As discussed under the first theme, the concept of community was consistently associated with understandings of a PHAPC. Here, data further suggested that this approach required a shift in thinking about the community. One participant said that building resilience in the wider community should become a goal. Another spoke of the limitations of a service delivery model where the community is passive, implying the need for more active participation on the part of communities. There was recognition that a PHAPC was a social model that acknowledged the role of community. In addition it was mentioned that there was a need for improved working alongside community organisations.

And a key thing there around death and dying being not just about health services or a medical issue, but that it's a much broader social issue and acknowledges how communities do most of the work...

#8

Two leaders implied that a PHAPC required a different way of thinking about volunteers. They should be seen as a powerful group with a range of existing skills and potential reach into the community, rather than a work-force to be trained to help professionals deliver services. The need to equip volunteers with skills and knowledge to reach beyond patients and families was highlighted.

Volunteers have a huge reach into our community...you get people from many and varied backgrounds...and so the volunteers add a richness, you know?

#14

Two leaders thought that a PHAPC required an enlarged thinking. Specifically acknowledging the many factors influencing the experience of death and dying was mentioned by one participant. The need to think beyond ones' own locality was raised by another who referred to a need for better awareness and support of national initiatives.

It's thinking about all the socio-economic determinants of health. Culture, sociological factors – the people that live within that society, communities, how they work. I don't know if I'm saying it very well, but that's what I think of.

#11

Participants raised a number of **challenges** associated with a PHAPC. Similarly to the barriers for community engagement (highlighted earlier in this chapter under theme two), two leaders spoke about the difficulty in understanding a PHAPC. One went on to explain that they felt 'hospice' and 'health promotion' were each complex terms on their own and were made even more difficult to grasp when combined. The other noted that the language, or terms were simply too technical.

And I think it's really important that any public health approach to palliative care...when you're trying to introduce the public to new approaches...it's got to be in plain speak. I've seen so many presentations on a sort of public health approach, and I've thought crikey it's so technicalised...

#13

So in some ways, much like hospice seems to be a perceptual issue for the general public, health promotion probably also is a bit of a perceptual problem as well when it comes to death and dying...I can understand that, because when people first came out with health promoting palliative care, I said, 'What?'

#12

In terms of endorsing a PHAPC, the data demonstrated **support** for the approach. Participants expressed that a PHAPC was the right direction for the future of hospices, and that public health and palliative care complemented each other. However, another two had never heard of a PHAPC, and prior to the interview had not even associated palliative care with public health. One of these incorrectly understood a PHAPC to be a fundamentally clinical model.

I wouldn't know. I wouldn't have linked them (public health and palliative care) together.

#5

I assumed it was more a DHB model – more clinical...After I googled it, I thought it did sound very, very similar (to their service model).

#4

4.4.4.2 Sub-theme 2 Contemplating models

A PHAPC is essentially a social model; therefore it has raised interesting deliberations around existing models of palliative care which do not have such a strong social focus. The essence of these discussions and the varied views are well-reflected in the data from the interviews with hospice leaders.

The first subject of this dialogue was around the **medical model of death**. Participants had varying feelings and thoughts on the topic. Five leaders agreed that the existing model of dealing with death within the health sector was over-medicalised, and one of these reflected that this was a historic problem. Two leaders were wary of supporting this notion. While they acknowledged that the phrase ‘over-medicalising death’ was commonly said and heard, they felt that a medical model was valuable and indeed made an important contribution toward the philosophy of providing holistic care. One leader felt this phrase was offensive and simplistic.

I couldn't agree more. (That death has been too medicalised).

#4

I think our care has in many ways become more medicalised, although sometimes I think we're a little unfair on ourselves...The medical model – it's still a very powerful model.

#11

In the discussions, participants identified what they felt were the problems with a medical model of death. Six leaders felt that a medical model resulted in potential negative consequences for people and communities. Two leaders felt that professionalising death de-skilled the community and fostered a paternalistic mentality within health care workers. Two leaders said that a medical model resulted in people being ill-prepared for a poor prognosis and for bereavement. One leader suggested that a medical model was medicines and solutions focussed. Another leader said that such a model focussed on aggressive treatment, which resulted in patients expecting aggressive treatment. Finally, one leader stated that a medical model was an exclusive model.

I think what we have done...health professionals as a whole...and perhaps over-medicalised is the easiest word to use, made death something that communities can't deal with, that this is something that belongs in the professional realm.

#8

To overcome these issues, a number of solutions were posed. These solutions all reflect the ideas of a more socially oriented model of death. Four leaders endorsed the need to ‘normalise death’ and by implication place it back in the hands of community. Three suggested a shift was required towards a more social model, while one stated that a balanced approach was required where a medical model was upheld but at the same time social models were further developed. One leader raised the fact that hospices providing social supports only were relatively new in New Zealand, and would need time to find their niche in the palliative care sector. The potentially constraining or liberating effects of funding contracts and sources, on scopes of work and therefore on models of care, was also mentioned.

It's about normalising death and bringing death back into the community, and dying.

#14

The **specialty model of palliative care** was the second topic of deliberation. Three leaders raised concerns over palliative care being a specialty. Two felt it resulted in a dependence on specialist services which was not sustainable in the long term. One felt it fostered a lack of preparation upstream, as dying was not seen to be within the remit of clinicians seeing people prior to a referral to palliative care. They also felt that having palliative care as a speciality resulted in discomfort with end-of-life issues in primary settings. Another leader felt that a specialty model was exclusive.

Yeah, and part of it is increasing their capacity to do what they can do so that everyone is less reliant on the very small specialist services.

#2

When you get to this point you realise this is a very different conversation (about a PHAPC) to providing medical care. And that's where it makes you reflect, are we doing the right thing by becoming very specialist? I think it's the specialist criteria as much as the medicalisation that we're practicing, to be cautious about, because we could be leaving a whole lot of people out.

#11

Again, participants showed varied support for the specialist model. While one leader expressly stated their view that hospices, or palliative care should not be a speciality at all, two were adamant of the need to retain the speciality element of palliative care in addition to adding a more social focus. These two spoke about the importance of maintaining the core business of hospices.

And it's a specialty now, you know, where we never intended it to be. When you think of Dame Cecily Saunders and her modern-day hospice movement, it was so to the contrary, wasn't it?

#14

Our core business is around providing specialist palliative care and so we need to be careful as an organisation that we don't lose sight of everything that goes into that. That we have to do really well, and that the whole concept of you know, the public health approach, we want to make it integral to what we do, but we have to meet all the expectations of a specialist provider as well.

#8

The way forward, as described by four of the leaders interviewed, was for palliative care to be better integrated into mainstream health care. Three specified the need for palliative care to be encouraged and developed outside of specialist provision.

And I think it's really important that everything is not just specialised if you like, because a lot of palliative care is provided, and can be provided by primary care and generalists. And we need to encourage that and foster it, and have that understanding in the broader community.

#1

4.5 Triangulation - Integrating the quantitative and qualitative data

After considering the findings of the quantitative and qualitative phases of the study separately, they were then integrated to see where the findings converged and where they diverged. Triangulating the data in this manner adds methodological rigour, as discussed in chapter three on the study methods. Integrating the data was considered in relation to the three parts of the research question. In all instances the findings demonstrated congruence, and there were no instances where the results from one phase contradicted the results from the other phase.

4.5.1 The uptake of a PHAPC

The uptake of a PHAPC by hospices in New Zealand was primarily answered by the survey which showed that 60% of hospices had prioritised this approach. Findings from the interviews confirmed strong support for a PHAPC.

4.5.2 The nature of a PHAPC

Findings from the survey showed that activities carried out under the banner of a PHAPC tended to fall at the weaker end of the community engagement spectrum, and most were for the benefit of the service. These findings were confirmed by the interviews which showed that most activities resembled social marketing of the service more closely than true community engagement designed to empower the wider community. Both phases of the study show that the nature of a PHAPC in New Zealand favours activities that involve informing, consulting and co-producing with the community as opposed to activities that involve collaborating and empowering.

4.5.3 The understandings of a PHAPC

The interview findings showed that most leaders could correctly identify the components of a PHAPC. However, findings from both components of the study demonstrate incomplete understandings of community engagement. The survey showed that the rationale for many activities was the benefit of the hospice service, and the interviews showed that many activities centred on core service provision. Both of these findings evidence partial insight into the concept because true community engagement is designed to benefit the broader community and is typically distinguished from core service provision.

4.6 Conclusion

The results from an online survey and telephone interviews with New Zealand hospice leaders has been presented in this chapter. The survey data revealed the uptake and nature of a PHAPC within New Zealand hospices. While there was significant support for a PHAPC, the nature of activities carried out reflected relatively low-powered community engagement according to the spectrum applied. The interviews aimed to further explore understandings of a PHAPC show mixed perceptions and feelings around the model and its' associated features. Four overarching themes were developed from the data. The themes were *taking stock: current understandings of a PHAPC, growing community engagement, new tools and recalibrating palliative care*. Further reflection on these results may be found in the following and final chapter 5.

Chapter Five Discussion of Results

5.1 Introduction

This thesis has presented a mixed methods study exploring a public health approach to palliative care (PHAPC) by hospices in New Zealand. This chapter discusses important elements of the results presented in chapter four. Rather than discussing the results according to the separate methods employed by this study, or along the lines of the major themes, I have opted to discuss the main findings as they relate to the three components of the research question – namely the uptake, nature and understandings of a PHAPC. This format assists with ease of reading, but also suits the underpinning philosophy of this study which is a pragmatic concern with addressing the research questions. The discussions under each heading will relate key findings relate to the current literature. The chapter will conclude with some recommendations from the study, as well as an acknowledgement of the study limitations and strengths.

5.2 Uptake of a public health approach to palliative care in New Zealand

The uptake of a PHAPC in New Zealand and some of the factors influencing this uptake will now be discussed. In addition some of the new ideas associated with this approach and some of the implications of supporting it will be considered.

5.2.1. Support for the approach

This study is the first to explore a PHAPC within the palliative care sector in New Zealand, and the first to confirm support for the approach in this country. The quantitative data has established that this new approach is a current priority in 60% of the sample of hospices in New Zealand. It is interesting to compare these results to the same survey as applied to palliative care services in the UK in 2013 (Paul & Sallnow, 2013). The results from the two countries are almost identical (see Table 5). However, one must be mindful that the survey captures uptake at one point in time, and that there is a three year time gap between the UK and New Zealand results. Therefore it would be more accurate to say that the level of support for a PHAPC in New Zealand is the same as it was in the UK three years ago. In the UK policies around end-of-life care have recognised elements of a PHAPC for some time (Department of Health, 2008; Scottish Government 2008). This strategic support continues to grow, the most recent example being the Scottish government's Strategic Framework for Action on Palliative and End of Life Care (Clark, 2015b). Currently no New Zealand national strategic documents for palliative care explicitly acknowledge a public health approach.

Table 5: Comparison of New Zealand and the UK survey results

| A Public Health Approach to Palliative Care | Current priority | Possible future priority | Not a priority |
|---|-------------------------|---------------------------------|-----------------------|
| New Zealand Hospices (54% response rate) | 60% | 33.3% | 6.6% |
| UK Palliative Care Providers (66% response rate) | 60% | 30.8% | 7.6% |

5.2.2 Factors influencing support

The adoption of a PHAPC means actively embracing community engagement as the chief method of working with community to improve end of life experiences (Sallnow & Paul, 2014). The qualitative data from this study has highlighted what hospice leaders have identified as enablers and barriers for community engagement. Identifying these influencing factors is important for facilitating the growth of the movement.

A number of factors were seen as enablers of the approach, these include being proactive, innovative and culturally responsive. In their model for community engagement, Sallnow and Paul (2014) include being proactive and responsive in their list of supporting factors. Innovation certainly is an implicit requirement of the approach which seeks new ways to support end of life care by empowering communities. The ‘compassionate communities’ approach is the most common outworking of a PHAPC (Kellehear, 2013). A report on activities being carried out in the UK under the banner of Compassionate Communities reveals a wide variety of creative programmes designed to strengthen community participation in their own well-being which includes death, dying and loss (Barry & Patel, 2013). The reputation or favour that hospices have with their local communities was also cited by participants in this study as an important facilitator of community engagement.

Besides these enablers, there are significant obstacles to the approach that will need to be overcome if community engagement is to succeed. Firstly, resources were mentioned as a barrier by a third of those interviewed. This was also identified by the respondents in the UK survey as a reason for not prioritising a PHAPC (Paul & Sallnow, 2013). Government funding for hospices in New Zealand is driven by service provision (Ministry of Health, 2001). Therefore, resourcing community engagement work which is not service-oriented is a shift for hospice and funders alike. Herrera, has identified time, resources and investments as some of the important challenges for implementing compassionate communities (Herrera, 2016). Participants in this study also raised the challenge of reporting or evidencing the ‘softer’ results stemming from community engagement activities when compared to the ‘hard’ measurable indicators of

service delivery. Encouragement and guidance for measuring the impact of a PHAPC has been underscored in recent literature (Rosenberg et al., 2016; Sallnow, Tishelman, Lindqvist, Richardson, & Cohen, 2016; Sallnow, Richardson, Murray, & Kellehear, 2016).

Secondly, paternalism was a barrier identified by New Zealand hospice leaders. This is a known obstacle for implementing a PHAPC which has been highlighted in the literature. Rosenberg, Mills and Rumbold (2016) report that, “the greatest barrier to collaboration can be formal caregiver’s inability to appreciate the complementary contribution of informal care, or to perceive how informal care may be disrupted by programmatic approaches of formal services” (p. 1).

Participants in this study spoke about professionals assuming that they were the only ones with knowledge of death and dying, and that they were best positioned to provide end-of-life care. Yet the positive effect of community action has been demonstrated in a recent systematic review (Sallnow et al., 2016). Paternalistic attitudes deny the skills, knowledge and abilities of the community to contribute meaningfully towards the care of the dying. It has been noted that professional services often adopt a needs or deficit-based view of the community, rather than an assets-based view that acknowledges these natural strengths that people have within themselves and their social networks (Rumbold & Aoun, 2014).

Lastly, participants in this study reported that community engagement, and indeed a PHAPC was a difficult concept to understand. The results from the literature review for this study bear out these conceptual challenges in that a PHAPC itself is viewed in three different ways – health promoting approach, a WHO approach and a population-based approach. Furthermore, the need for developing clarity around some of the key terms associated with a PHAPC has been acknowledged by those advocating the approach (Sallnow & Paul, 2014). Some of the difficulties in fully understanding a PHAPC are discussed further along in this chapter.

5.2.3 New ideas

‘New tools’ was one of the themes created from the qualitative data. The two specific concepts addressed in the interviews with participants were social networking and death cafes.

Social networking is a model of identifying and mobilising peoples’ informal social networks as a means of sharing care, supporting family caregivers and empowering the wider community with skills (Noonan et al., 2016; Horsfall et al, 2012; Abel et al, 2013, Abel et al., 2011). There are many documented examples in the international literature of how this concept has been successfully applied in countries such as Australia (Horsfall et al., 2012), the UK (Abel et al., 2011) and India (Kumar, 2007). While the data from this study

showed low formal awareness of the model, participants were very supportive of the concept. In fact without calling it social networking, a number of hospice leaders felt they were already applying the principles of this model at their hospices in the way they worked with patients, families and the significant people in their lives. It is conceivable that greater insight into this framework (Abel et al., 2011; Abel et al., 2013) would assist in promoting a more considered approach and enhance the development of this model in New Zealand.

Among older people, loneliness associated with a lack of social relationships is a growing concern (Victor & Yang, 2012; Gardiner, Geldenhuys & Gott, 2016). This study confirms that hospice leaders are acutely aware of social isolation in this age group, and in fact they identified this as a particular challenge for applying a social networking model. However, hospice leaders were divided about whether or not addressing this malady without palliative need was within the remit of hospice services. Yet, the case for integrating of palliative care and gerontology has been well presented (Gott & Ingleton, 2011). Disparities in access to palliative care for older people have been evidenced in the literature (Lloyd et al., 2016) prompting the WHO to call for a palliative care approach to be routinely adopted in the care of older people (Davies & Higginson, 2004). Interestingly, the issue of ageism in hospices was raised in this study in the context of widening referral criteria to accommodate the social needs of older people at the end of life. While there is certainly evidence that suggests ageism is a problem within health care in general (Mellor, Chew & Greenhill, 2007; Eymard & Douglas, 2012), in the hospice context the evidence points more to the challenge of recognising palliative need rather than ageism per se (Lloyd, 2006).

Death cafes are one of the popular new tools associated with a PHAPC, and are being upheld by many palliative care services across the world as a means of getting people to talk more openly about end-of-life issues (Adler, Remer, Coulter & Miller, 2015). The official Death Cafe website lists that 31 death cafes have taken place in New Zealand, 157 in Australia and 678 in the UK (Death Cafe, 2016). Despite growing support for the death cafe movement, leaders at hospices in New Zealand had markedly ambiguous feelings about them. While there was some backing for them, most of the participants were cautious or uncertain about their value, showing particular aversion to the terminology. Arguably, it is precisely this discomfort that death cafes seek to address. No literature exploring health care professionals' attitudes towards death cafes could be found.

5.2.4 Implications of supporting the approach

The uptake of a PHAPC has implications for hospice services; in particular support for a PHAPC has kindled an intense introspection of the models traditionally employed by palliative care. This is part of the re-fashioning that Rosenberg, Mills and Rumbold (2016) allude to. The theme from the interview data, 'recalibrating palliative care' confirms this contemplation. Participants thought a PHAPC required shifts in thinking about the position of palliative care at the end of life only, about the community being passive recipients of services and about volunteers being more just a work-force. These changes in philosophy have

been widely discussed in the literature, especially in the foundational works on the approach by Kellehear (1999a; 1999b; 2005).

Participants in this study contemplated the medical model of death. The professionalisation of death has been identified in the literature and is widely accepted as one of the motivations for the PHAPC (Rosenberg et al., 2016). However the medical model of death versus a social model of death remained a hot topic for participants in this study. While a number of hospice leaders agreed that a medical model had led to negative consequences for communities in that they were de-skilled in the issues of death and dying, there was also strong support for the value and contribution of the medical model to date. It was also noted that the term ‘over-professionalising’ death was probably a more accurate description than ‘over-medicalising’ death. The strong feelings expressed on this matter seemed to indicate a belief that the professional and social models were mutually exclusive, and one had to argue the case for which was better. However, it should be noted that the chief proponents of a PHAPC have consistently maintained that adopting a social model does not mean excluding the medical model, but rather acknowledging the important contribution of both (Abel et al., 2013).

Similarly, palliative care being a specialty raised intense and diverse feelings. Some leaders felt palliative care should not be a specialty, and concerns were raised that a specialty model perpetuated an unsustainable dependency on professional services, fostered exclusivity and a de-skilled of health care workers in other settings, all of which are opposed to the documented goals of a PHAPC (Kellehear, 1999a). However, others stated that it was important for hospices to retain and further develop palliative care as a speciality. The recognition of palliative medicine as a specialty has been widely debated since it came about in the UK in 1987, and in New Zealand in 2001 (Clark, 2014). While many see the specialty status as important for the integration of palliative care into health systems and long-term sustainability of the discipline, there are others who argue that palliative medicine is better positioned and more accessible if positioned within general medicine (Clark, 2014). To date, a PHAPC has not taken a position in this debate, however it has been made clear that the movement does not negate the need for specialist palliative care (Abel et al., 2013).

5.3 The nature of a public health approach to palliative care in New Zealand

The nature of a PHAPC in New Zealand is most acutely revealed in the findings related to community engagement. Community engagement is a term closely related to a PHAPC. The aim of community engagement is to build capacity in the wider community around end-of-life care (Sallnow & Paul, 2014).

Results from the quantitative phase of this study have shown that the bulk of activities carried out by New Zealand hospices under the umbrella of community engagement fall at the weaker end of the community engagement spectrum. The nature of most activities was informing, consulting and co-producing rather than

collaborating and empowering. The reason why this end of the spectrum is considered weaker is because community involvement in these activities is more passive, and consequently less owned by the community, and therefore less able to achieve lasting impact in the community (Lane & Tribe, 2010; Sallnow & Paul, 2014).

The qualitative findings of this study confirm the quantitative findings. ‘Community engagement skewed to the left’ was one of the sub-themes under the theme ‘growing community engagement’. Most of the descriptions of activities labelled as community engagement were found to resemble marketing of the services more closely than true community engagement designed to empower the broader community. This is evidenced in that the dominant aims of activities were reported as being to raise awareness of the service, to raise funds, and to recruit volunteers. This trend to favour activities on the left of the spectrum (inform and consult-type activities) has been noted by proponents of the approach and is not unique to New Zealand (Rosenberg et al., 2016).

These findings highlight an important implication for the development of this approach in New Zealand. Although there is support for a PHAPC in New Zealand, community engagement activities will remain relatively low-powered to achieve enduring changes within the community, as long as informing-consulting type activities are favoured over the more powerful collaborative, co-production and empowering type activities (Lane & Tribe, 2010).

5.4 Understandings of a public health approach to palliative care in New Zealand

This final section considers the understandings of a PHAPC in general, and then understandings around community engagement specifically.

5.4.1 Understanding a public health approach to palliative care

The theme from the qualitative findings ‘taking stock; current understandings of a PHAPC’ shows that hospice leaders in New Zealand have a fair understanding of the approach. Most correctly identified education, community, a population perspective, and health promotion as the key concepts related to a PHAPC. These elements form some of the foundations of the approach (Kellehear, 1999a). However, 13.3% of those interviewed for the qualitative phase of the study had not previously heard of a PHAPC. This demonstrates that further development and promotion of a PHAPC is required.

This study has shown that a PHAPC is a challenging concept to grasp. In particular, the technical nature of the terminology, and the confusion associated with merging the complex concepts of public health and palliative care were both highlighted by participants as obstacles to understanding. The literature confirms

this and identifies a number of factors that make understanding the approach complex. Firstly, a PHAPC represents a novel model for palliative care - a more social approach (Rosenberg et al., 2016; PHPCI, 2015). In addition, the approach comprises of a combination of ideas from two disciplines – those being palliative care and public health (PHPCI, 2016; Rosenberg & Yates, 2010). Each of these disciplines have broad definitions which have evolved over time (Pastrana, Junger, Ostgathe, Elsner & Radbruch, 2008; Winslow 1920; WHO, 1986). Furthermore, a number of public health frameworks for palliative care exist (Rosenberg et al., 2016), and indeed the literature review for this thesis confirms this. Finally, there is also a surfeit of terms associated with a PHAPC (Paul & Sallnow, 2013) which can be difficult to assimilate.

5.4.2 Understanding community engagement

PHAPC is inextricably linked with community engagement; in fact the terms have been used interchangeably (Sallnow & Paul, 2014). It is therefore imperative to consider understandings of community engagement. The findings from this study suggest that hospice leaders in New Zealand have incomplete understandings of true community engagement as it relates to a PHAPC. This conclusion is made based on two important trends in the data which are now considered.

Firstly one of the distinguishing features of true community engagement, as raised previously, is that it aims to benefit the broader community (Sallnow & Paul, 2014). Work is purposively co-designed to improve skills and end-of-life outcomes in the general public (Rosenberg et al., 2016). In this study there were certainly descriptions of this type of work being carried out. However, the bulk of the work described had as its' rationale the perceived gain of the hospice service in terms of improved uptake and relevance of services. Even descriptions of empowering the community were predominantly associated with the provision of services in the community such as fundraising and volunteering. Therefore it may be questionable to even call such activities community engagement, since the principal aims are different. It has been suggested that activities that do not explicitly aim to develop community capacity, sit on the far left of the spectrum at best (Sallnow & Paul, 2014).

Secondly, the authors of the prominent model for community engagement in end of life care have highlighted that core service provision is essentially different to community engagement (Sallnow & Paul, 2014). Yet this distinction was not made by participants in this study, which points to an incomplete understanding of community engagement. The majority of work described as community engagement had a focus on caring for patients and families. This is essentially the core business of hospices and therefore differs from community engagement.

Despite the bulk of the data pointing towards incomplete understanding of true community engagement, it is crucial to note that there was unanimous support for the concept in that all the respondents of the survey and participants in the interviews felt that they were doing it. The participants in this study understood community

as being related to people, places or both. This understanding echoes the broad definition proposed by National Institute for Health and Clinical Excellence (2008). Māori and ethnic minorities were consistently identified as the groups most difficult to engage with. Some work has been done abroad on guidelines for community engagement with ethnic minorities (Lane & Tribe, 2010). In New Zealand, very little guidance exists for the hospice specific context; however the Te Arai group at the University of Auckland have developed a number of useful resources for engaging and empowering Māori at the end of life (Gott et al., 2016).

5.5 Recommendations from the study

A number of recommendations may be made from the findings of this study:

Recommendations for policy

- Recognition of a PHAPC nationally in policy documents
- Strategic planning that incorporates a PHAPC at district health board level
- Emphasis on the fact that a PHAPC does not negate the need for specialist services

Recommendations for practice

- Development of a deeper understanding of a PHAPC and the spectrum of community engagement in end-of-life care
- Promotion of discussion around challenging concepts associated with a PHAPC in order to improve conceptual clarity
- Evaluation of programmes that adopt a PHAPC to build the evidence base for a PHAPC
- Intentional addressing of barriers to a PHAPC, such as paternalism

Recommendations for future research

- More guidance is needed on engaging specific ethnic communities in New Zealand around end-of-life issues
- Death cafes - exploring reluctance and evaluating the benefits thereof
- Continued commitment to establishing conceptual clarity of a PHAPC
- The social needs of older people nearing the end of life – the role of hospices and the debate over widening referral criteria
- Exploring and tracking changes in models of palliative care, specifically any shifts towards a more social model as upheld by a PHAPC

5.6 Strengths of the study

This study is the first to explore a PHAPC in New Zealand and the first determine support for the approach within local hospices. It therefore adds weight to the call for a PHAPC to be prioritised in the strategic planning of end-of-life care locally, regionally and nationally.

The use of a mixed method approach adds confidence in the study findings in that the results from the quantitative and qualitative phases are congruent in the ideas and trends they identified.

Furthermore, the findings from this study help facilitate the development of a PHAPC in New Zealand by identifying the known barriers and opportunities.

5.7 Limitations of the study

With regards the quantitative phase of the study, external validity was limited by the response rate, and therefore while the study has highlighted trends it does not speak to all the hospice services in New Zealand. As with all surveys, the study findings reflects the data at one point in time, and are therefore limited to that time frame.

Related to the qualitative phase of the study, it is possible that those with a particular interest in a PHAPC were those who chose to participate in the interviews. This may have introduced a bias in their knowledge or support for the approach. In addition, the data may have been somewhat limited by the semi-structured nature of the interview schedule.

5.8 Conclusion

There is clear support for a PHAPC by hospice leaders in New Zealand, in that more than 90% of respondents to this study have either currently prioritised this approach or plan to do so in the future. This is the first study to confirm support for the approach and therefore it affirms the importance of including the PHAPC model in discussions regarding the future direction of palliative care services in this country. However, conceptual challenges will need to be addressed if the model is to be applied meaningfully. Community engagement in particular needs to be reviewed in light of the guiding literature from those who have experience in this new approach. A distinction should be made between core service provision and community engagement. In addition community engagement needs to move away from social marketing of the service, and move towards the more powerful activities that involve collaboration, co-production and empowerment of the broader community.

APPENDIX 1 – Codebook for literature review

| Code Book Literature Review | | |
|---------------------------------------|--|---|
| Author and country | Data extracts used for coding | Codes |
| Bellamy et al. 2014 New Zealand | "As such, the findings from this study resonate with the work of Kellehear (2005) whose work in relation to public health and end-of-life care shows how communities might provide care for bereaved individuals where statutory provision is scarce – something akin to a 'third wave' movement of public health (Kellehear 2005)." p. 102 | communities as providers |
| Benzein & Saveman 2008 Sweden | "The conversations about hope and suffering had a salutogenetic approach ...which involved acknowledging the families' resources rather than their deficits . The conversations were focused on the experience of health rather than illness and were intended to encourage the families to reflect on their life situations...." p.440 "The results of this small study show that there is a need to implement health-promoting conversations about hope and suffering as a natural part of the caring relationship between health professionals and families in the palliative context." p.445 | resources vs deficits wellness focus |
| Horsfall et al. 2012 Australia | "Mobilising, using and developing caring, or compassionate, informal networks through active engagement in tasks promotes a model of change which moves away from the more usual health promotion approach which is to educate the community so that they can participate. Rather this model of change supports networks of people to participate in the day-to-day tasks of caring for people." p. 381 "When caring generates social capital , it no longer just addresses a private need but potentially contributes to a public good, a resource that can be used by the network or community members to address other community needs. It also models both the practice of caring and the caring society. " p.381 | active vs passive participation social capital |
| Leonard et al. 2015 Australia | "The research supports the value of third generation social network analysis and the potential for end-of-life caring to build social capital ." p.153. "Using a community development model to encourage the growth of caring networks in EOL care can benefit carers and spread the word that dying is part of living, not the special domain of the medical profession ." p. 158 "Rather it (this study) has shown the possibility of using a third-generation social network approach to demonstrate community development through EOL caring ." p. 158 | social capital caring networks vs professionalization community development |
| Lewis 2014 Australia | "The social capital approach to understanding needs and capacities of lower socioeconomic populations is important for understanding the contribution of networks and relations to buffer the levels of disadvantage in health populations" p.7. "Understanding the relations and networks of support for lower socioeconomic populations with end of life care needs is invaluable for supporting the increased needs of this group and ascertaining a rich description of their social milieu. A more sustainable and considered health promotion approach to palliative care, which shifts attention away from health service development to consider the resources which likely engender community engagement and can ensure greater sustainability of resources for patients and carers at the end of life is needed." p. 7 | social capital capacities networks sustainable community engagement vs health service development |

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| Lindqvist 2015 Sweden/international | <p><i>In recent years, breaking death-denying taboos and promoting occasions for awareness and reflection about death has been argued to have beneficial effects by social psychologists, sociologists, policymakers and others in a variety of settings ... Kellehear and Sallnow (2012) have framed such endeavours within the concepts of new public health and what is termed, "health-promoting palliative care". P.7.</i></p> | breaking taboos awareness reflection |
| McIlfatrick et al. 2013 Ireland | <p><i>"The World Health Organisation has advocated palliative care as being a public health issue: access to such care is acknowledged by United Nations conventions as a human right. Although many governments generally adhere to this claim, placing palliative care within public health strategies, translation into practice varies widely." p.2.</i></p> <p><i>"The theoretical basis for the public health approach to palliative care has been led and developed in Australia by the work of Kellehear and O'Connor. Various international examples from India, Australia; and the UK, have clearly demonstrated the importance of such approaches in increasing access to palliative care services and improving understanding and awareness." p.5</i></p> <p><i>"Low levels of understanding highlight the need for a parallel approach ensuring that palliative care is more integrated into health service systems alongside a continued public health approach to palliative care in order to eradicate social taboos and ensure such services are sought out when required." p.6</i></p> | parallel approach BOTH WHO (access, strategies, integration, health systems) PHAPC (access, awareness, social taboos) |
| McIlfatrick et al. 2014 Ireland | <p><i>"Public health palliative care or health-promoting palliative care is concerned with building public policies that support dying, death, loss and grief; create supportive environments; strengthen community action and allow people to develop personal skills in these areas." p.273</i></p> <p><i>"Palliative care and public health services should work together to develop health promotion, which will benefit palliative care and will be effective in changing public knowledge, attitudes and behaviour by combining the paradigms of public health and end-of-life care." p.279</i></p> | goals of health promoting palliative care changing knowledge, attitudes and behaviour |
| Mills et al. 2015 Australia | <p><i>"In restoring community ownership and agency, the public health approach of health-promoting palliative care (HPPC) may contribute to change through the building of community capacity. However, current understandings of such capacity building for end-of-life care are both limited and service provision oriented." p. 219</i></p> | community agency vs service provision |
| Paul & Sallnow 2013 UK | <p><i>"Public health is a broad term focused on improving the health of populations, but the changing health landscape has necessitated new ways of working, beyond traditional public health measures. The importance of engaging communities in their own care has been recognised, and this now occupies a central place in many fields in health." p.196</i></p> <p><i>"A range of terms exists to describe these approaches, including a public health approach, health-promoting palliative care and compassionate communities." p.196</i></p> <p><i>"The theoretical basis for the public health approach was developed in Australia by Kellehear.... Examples published from India, Australia and the UK describe the role community engagement has played in both increasing access to services and improving the holistic nature of care." p.197</i></p> | community engagement vs traditional public health measures access holistic care |
| Pizzi 2014 U.S. | <p><i>"Health promotion is defined by the Ottawa Charter..." p. 213.</i></p> <p><i>"With a foundation in health promotion, health professionals can adapt their skills and talents for the terminally ill and their families and explore more deeply the concept of facilitating a good death." p. 214</i></p> <p><i>"To most of the participants in the study, treating holistically and viewing people at the end of life through a holistic lens was equivalent to promoting health and well-being at the end of life." p.217</i></p> | a good death holistic care |

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| Stajduhar et al. 2011 U.S. | <p>"Home-based family caregivers are often assisted by home care services founded upon principles of health promotion, such as empowerment." p.79</p> <p>"The long-term goal of empowerment was characterized as client self-care and/or family care and decreased dependence on formal services." p.79</p> <p>"It has been suggested, for instance, that a health promoting approach to palliative care helps to foster a sense of control in terminally ill patients (Kellehear, 1999). Patient and family empowerment is viewed as promoting physical and mental health, enhancing the quality of care, promoting autonomy, and containing service-delivery costs" p.79</p> | empowerment |
| Aoun et al. 2014 Australia | <p>"This paper outlines a pilot study providing tentative empirical support for the public health model of bereavement support and provides the basis for a larger, population-based study.....Currently, there is a lack of clear evidence to guide development and allocation of bereavement programs in palliative care, including programs to develop community capacity. A larger survey will enable us to fill this gap and to determine how the support needs of each of the three groups of bereaved people should be serviced. This is of utmost importance for cost-effective and equitable resource allocation, and for understanding the contribution the community at large makes to bereavement support." p. 478</p> | population based service provision community capacity costs equity community contribution |
| Lupu et al. 2013 U.S. | <p>"A public health approach to palliative care involves applying the population-based view that is the essence of public health to a health problem, service-delivery issue, or health policy challenge. It entails using the tools of public health (such as epidemiology, health services research, and policy analysis) to characterize and solve a health issue.....Only a public health approach will provide the needed information and analysis to improve care at the system level." P.1583</p> | population based tools of public health systems focus |
| Wilson et al. 2013 Canada | <p>"From a public health perspective, it is critically important to take public preferences into account when developing EOL care strategies." p.502</p> <p>Despite the need for qualitative and other research to establish why widowhood is a major place predictor and why most people chose the home over other places for their final days, the widespread home preference indicates public health interventions are needed to promote good home deaths. As palliative care is not yet fully Integrated into the public health agenda, it is an area with great potential" p.507</p> | population based survey (title) preferences predictive relationships good home deaths integration |
| Gilson et al. 2013 International | <p>"The primary aim of this study was to examine countries' government and health-care system influences on opioid availability for cancer pain and palliative care" p.105</p> <p>'Palliative care development level'—categorized as (1) countries that had some level of palliative care activity within the mainstream health system or (2) countries with no integrated or generalized palliative care activity." p.107</p> <p>"This study represents the first multivariate statistical analysis of INCB (International Narcotics Control Board) consumption data to empirically account for a variety of country-level factors related to public health....A parsimonious statistical model was developed to explain the predictive relationships between national indicators and opioid consumption, as a means to identify implications for improving appropriate access to opioids." p.108</p> <p>"Instances of stakeholders' actions to promote safe and appropriate opioid access to improve pain relief and palliative</p> | health care systems palliative care development linked to integration epidemiology exposure variable (country level factors) outcome variable (access to morphine) |

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| | <p>care servicesSuch country- or state-level activities fall into one of three domains of the WHO public health approach to developing palliative care" p.110</p> | country/national level WHO |
| Grant et al. 2011 Uganda, Kenya, Malawi | <p>Holistic palliative care can be delivered effectively in the face of poverty, but a public health approach is needed to ensure equitable provision." p.1</p> <p>"Various palliative care programmes have developed, and national palliative care associations have emerged, but despite this positive change, palliative care is still only available to less than 5% of those in Africa who need it."p.1</p> <p>"While these three programmes greatly benefit a fortunate few in each area, a public health approach with integration into government policy and core health service provision is necessary to significantly impact the national burden of palliative care needs in each country."p.10</p> | equity programme development access/reach integration policy service provision/systems national needs burden |
| Logie 2012 Zambia | <p>The WHO strategy to develop a public health system of palliative care at the national level proposes a quadripartite approach: policy, education, drug availability and implementation.... For palliative care to thrive in any resource-poor country it must be integrated into the public health system and secure long-term funding" p.264</p> <p>"Currently, palliative care can only reach a fraction of those who need it.....The cost of running hospices and palliative care organisations is not sustainable without either funding from significant donors or from central government." p.269</p> | WHO health systems national level integration reach sustainability/funding |

APPENDIX 2 – Ethics approval letter

Office of the Vice-Chancellor
Finance, Ethics and Compliance



The University of Auckland
Private Bag 92019
Auckland, New Zealand

Level 10, 49 Symonds Street
Telephone: 64 9 373 7599
Extension: 87830 / 83761
Facsimile: 64 9 373 7432

UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

03-May-2016

MEMORANDUM TO:

Prof Caryl Gott
Nursing

Re: Application for Ethics Approval (Our Ref. 016999): Approved

The Committee considered your application for ethics approval for your project entitled **The uptake of a public health approach to palliative care by hospices in New Zealand.**

We are pleased to inform you that ethics approval is granted for a period of three years.

The expiry date for this approval is 03-May-2019.

If the project changes significantly, you are required to submit a new application to UAHPEC for further consideration.

If you have obtained funding other than from UniServices, send a copy of this approval letter to the Research Office, at ro-awards@auckland.ac.nz. For UniServices contracts, send a copy of the approval letter to the Contract Manager, UniServices.

In order that an up-to-date record can be maintained, you are requested to notify UAHPEC once your project is completed.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals. If you wish to do so, please contact the UAHPEC Ethics Administrators at ro-ethics@auckland.ac.nz in the first instance.

Please quote reference number: **016999** on all communication with the UAHPEC regarding this application.

(This is a computer generated letter. No signature required.)

UAHPEC Administrators

APPENDIX 3 – Participant information sheet



**MEDICAL AND
HEALTH SCIENCES**
SCHOOL OF NURSING

The University of Auckland
Private bag 02019
Auckland 1142
New Zealand
Telephone 09 923 7563

Participant Information Sheet

The Uptake of Public Health Approaches to Palliative Care by hospices in New Zealand

Name of researcher: Colleen Dempers

Name of Supervisor: Merryn Gott

Researcher introduction

My name is Colleen Dempers, a Master of Health Science student at the University of Auckland. I am also currently employed at Cranford Hospice. My supervisor is Merryn Gott, Professor of Health Sciences at the University of Auckland.

This project

Rationale: The public health palliative care movement is gaining momentum globally, and it would be useful to gauge support for this approach locally.

Aim: This study will specifically consider the current uptake, nature and understanding of the public health approach by hospice services in New Zealand.

Duration: Data collection will take place during 2016 and the study should be complete by the end of 2017.

Benefits: This study will establish baseline data on public health palliative care initiatives, as well as informing the need for clarity around some of the terms and methods associated with this approach.

Risks: I do not anticipate any risks associated with this study or its outcomes, however should you feel that you have are at risk, or have been placed at risk, please feel free to contact the research supervisor Merryn Gott on the contact details below.

Funding: This study is funded by the student personally.

Invitation to participate:

As a strategic leader of a hospice service, you are invited to participate in this study. You may appoint a designated member of your leadership team to participate in your place. Participation is completely voluntary and declining to participate or withdrawing, will not result in a penalty of any kind.

Project procedures:

The research comprises of two phases.

Phase I is an online survey - if you consent to participating simply go ahead, click on the link in the email and complete the survey. This should take approximately 15 minutes to complete.

Phase 2 consists of telephone interviews – if you consent to taking part in a short interview, please indicate this at the last question of the online survey by filling out your contact details. Please note that if you provide your contact details, these will be kept confidential, and your identity will not be made known (this applies to both the survey and the interview). I will then be in touch to arrange the signing of a consent form, and to set up a 30 minute appointment at a time that suits you. Please note the interview will be audio-recorded and transcribed to assist in data analysis. You may choose to refuse answering any question and terminate the interview at any point. The student researcher will do the transcribing. You will be sent a copy of your interview transcript (within 2 months of the interview) and be given the opportunity to edit it (to be returned within 2 weeks).

Data storage, retention, destruction and future use:

Hard copies of the data collected by the online survey and by the telephone interviews will be stored in a locked filing cabinet, and electronic copies on a secure password protected computer at the School of Nursing at the University of Auckland. After 6 years, hard copies will be shredded and electronic copies permanently deleted.

Right to withdraw:

Once you have completed the online survey, you may withdraw your response by contacting the researcher up to one month post survey closing date. If you take part in the telephone interview, you may withdraw your interview data up to one month after the interview.

Anonymity and confidentiality:

In both the survey and the interviews, your responses will not be anonymous, but will be kept confidential... The confidentiality of individuals and hospices will be protected in the way that the data is reported or published. A copy of the research findings will be made available to you should you wish upon request. The findings will be submitted as an abstract to the Hospice New Zealand bi-ennial conference that takes place subsequent to the completion of the study.

| Student researcher | Supervisor | Head of Department |
|--|--|----------------------------------|
| Colleen Dempers cDEM747@aucklanduni.ac.nz 06-8787047 (Cranford Hospice) | Merryn Gott m.gott@auckland.ac.nz 09 373 7599 | School of Nursing 09 373 7599 |

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711.

Email: ro-ethics@auckland.ac.nz.

Approved by the University Of Auckland Human Participants Ethics Committee on 3 May 2016 for three years. Reference Number 016999

APPENDIX 4 – Consent form telephone interviews



**MEDICAL AND
HEALTH SCIENCES**
SCHOOL OF NURSING

The University of Auckland
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Auckland 1142
New Zealand
Telephone 09 923 7563

CONSENT FORM

THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS

Project title: *The Uptake of Public Health Approaches to Palliative Care by hospices in New Zealand*

Name of researcher: Colleen Dempers
[cdem747@aucklanduni.ac.nz](mailto:cadem747@aucklanduni.ac.nz)

Name of Supervisor: Merryn Gott
m.gott@auckland.ac.nz

I have read the participant information sheet and I 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.
 - My participation is voluntary.
 - I understand that I am to be interviewed over the telephone at a time that suits me.
 - I understand the interview will take approximately 30 minutes.
 - I understand that the interview will be audio-recorded and transcribed
 - I understand that I will be sent a copy of the transcript within 2 months of the interview, and be given the opportunity to edit it and return it within 2 weeks.
 - I understand that I am free to withdraw participation at any time without giving a reason, and to withdraw my traceable data up to one month after the telephone interview.
 - I understand that data will be kept for 6 years, after which time any data will be destroyed.
 - I understand that this interview is not anonymous, but that it is confidential, and that neither the identity of myself nor my hospice will be made known in any dissemination of the findings from this study.
 - I wish to have a summary of the findings emailed to me at this address:
-

Name: _____

Date: _____

Signature: _____

Approved by the University Of Auckland Human Participants Ethics Committee on 3 May 2016 for three years. Reference Number 016999

APPENDIX 5 – Approval to use survey tool

RE: Thesis - Microsoft Edge

Microsoft Corporation [US] outlook.office.com/owa/?viewmodel=ReadMessageItem&ItemID=AQMkADNIMjBINGU0LTA2NTI1NDM5Ni1hZDlkLTYSMTEBN2YzZjkwoQBGAAADo0Myy4SEAJNGlzx%2FXaR5IBHAOTzuF1H5IBCVS3nml.

Reply all | Delete | Junk | ...

Dear Colleen,

Lovely to hear from you and hear about your research. I'd definitely be happy for you to use our survey tool too and will send you a copy as soon as possible. [REDACTED]
[REDACTED] however once I return to the office (which should be tomorrow) I will have access to it and can send you a copy. If, by any chance, I don't remember to do this please send me a reminder email.

Many thanks

Sally

Dr Sally Paul
Lecturer, Social Work
Lord Hope Building, Level 6
University of Strathclyde
(0141) 444 8756

From: Libby Sallnow [libbysallnow@gmail.com]
Sent: 17 November 2015 13:46
To: Colleen Dempers
Cc: Sally Paul
Subject: Re: Thesis

Dear Colleen

I am so sorry for the delay in getting back to you. [REDACTED] I am sure Sally and I would be really happy for you to use our survey tool. Sally may have access to the original questions more easily than I at the moment but I'll also have a look.

I'll get back to you shortly!

With best wishes and sorry again for the delay, Libby

Welcome to the survey of hospices and community involvement

The survey consists of 6 questions and takes about 5 minutes to complete. It is completed anonymously and can be saved part way through.

1. Where is your hospice located?

| | |
|--|--------------------------|
| | Scotland |
| | Wales |
| | Northern Ireland |
| | North East England |
| | North West England |
| | East Midlands |
| | West Midlands |
| | Yorkshire and Humberside |
| | Eastern England |
| | London |
| | South East England |
| | South West England |

2. Does your hospice serve mainly a rural, urban or mixed population?

| | |
|--|-------|
| | Rural |
| | Urban |
| | Mixed |
| | Other |

3. What services does the hospice offer?

| | |
|--|----------------|
| | Inpatient beds |
| | Home care |
| | Day Hospice |

4. There has been a recent interest in social approaches to end of life care, such as compassionate communities, health promoting palliative care or a national conversation about death, dying and loss.

Is this something that is a priority for your service currently?

| | |
|--|--|
| | Yes |
| | No - this is not within the remit of the hospice services the hospice provides |
| | No - we do not have the resources to take this forward |
| | No - not at this time but possibly in the future |
| | No - other |

5. Has your service undertaken any of the following projects?

| | |
|--|---|
| | Working with local schools about loss, death, dying and/or hospice care |
| | Providing public education and awareness events |
| | Working with faith groups around loss, death, dying and/or hospice care |
| | Supporting community dialogue about end of life issues |
| | Engaging with local media on issues related to loss, death, dying and hospice care |
| | Engaging with local businesses on issues related to loss, death, dying and hospice care |
| | Attending community events as a hospice such as markets or festivals |

If you have ticked any of the boxes listed above, please describe which projects you felt were most successful and why.

6. Please feel free to add any comments you have on the role of hospices in relation to social approaches to end of life care (such as compassionate communities, health-promoting palliative care, or a national conversation about death, dying and loss)

| |
|--|
| |
| |
| |

We anticipate following up a small number of responses to find out a little bit more about the ways in which hospices work with communities. If you are happy to be contacted again in the future please leave your name, hospice, contact telephone number and email below

| |
|--|
| |
|--|

Please tick this box if you would like to receive a copy of the findings from this survey
(Optional)

Many thanks for your help and support with this survey.

APPENDIX 7 – Map of theme development

| Descriptive codes | Analytic codes/Categories | Sub themes | Themes | |
|--------------------------|-------------------------------------|--|--|--|
| 5 | Internal influences | Prompts | Taking stock - current understandings of a PHAPC | |
| 8 | External influences | | | |
| 9 | Community | Popular elements | | |
| 4 | Population perspective | | | |
| 11 | Education | | | |
| 3 40 | Health promotion | | | |
| 11 | People | Descriptions of community | Growing community engagement | |
| 4 | Places | | | |
| 1 | Both | | | |
| 19 | Hard-to-reach groups | | | |
| 44 | Low level community engagement | Community engagement skewed to the left | New tools | |
| 22 | High level community engagement | | | |
| 24 | Barriers | Influencing factors | | |
| 12 137 | Enablers | | | |
| 16 | Awareness | Limited formal knowledge of a social network model | New tools | |
| 3 | Support for the concept | | | |
| 3 | Doing it already | | | |
| 21 | Social isolation as a challenge | | | |
| 6 | Other challenges | Death café uncertainty | Recalibrating palliative care | |
| 9 | Support for | | | |
| 5 | Semantics | | | |
| 11 | Uncertainty | | | |
| 4 78 | No way | Changes and challenges that a PHAPC brings | Recalibrating palliative care | |
| 15 | Potentially new foci | | | |
| 6 | Challenges | | | |
| 5 | Support for | Contemplating models | Recalibrating palliative care | |
| 35 | Medical model of death | | | |
| 14 75 | Specialist model of palliative care | | | |
| 330 | 28 | 10 | 4 | |

APPENDIX 8 – Copy of publication of literature review

<http://dx.doi.org/10.1080/09699260.2016.1189483>

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Which public health approach to palliative care? An integrative literature review

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Background: Public health and palliative care are both broad disciplines with blurred boundaries. There is growing support for an alignment of palliative care to public health. Given the novel nature of this alignment and the ambiguity of the parent definitions, there is an understandable lack of clarity around this merged model.

Methods: The aim of this study is to describe the theoretical features of the public health approach to palliative care as articulated in the current research literature. An integrative literature review was conducted using systematic methods to identify qualitative and quantitative studies that expressly support such an approach.

Results: The search identified 18 studies. A thematic synthesis of these studies identified three different paradigms of a public health approach to palliative care within the current empirical research. These were defined as a *health-promotion approach* focussed on empowerment at community level, a *World Health Organisation approach* which focussed on systems at country level, and a *population-based approach* which typically viewed palliative care issues from an epidemiological perspective.

Conclusion: This review highlights that the public health approach to palliative care is understood in various ways. It is important that future research studies clarify which public health approach they are referring to.

Keywords: Palliative care, End of life, Public health, Health promotion, Theory, Models, Frameworks

Introduction

Although many countries have adopted their own definition of palliative care, most are based upon that proposed in 2002 by the World Health Organisation (WHO), which states that:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹

This definition goes on to clarify that palliative care is appropriate early on in the disease, and that it is also applicable to patients with non-cancer diagnoses. Both these points were lacking in the earlier 1990 definition.² Changes such as these have added breadth, and possibly ambiguity to what constitutes palliative

care.³ In addition, Pastrana *et al.*⁴ have eloquently described how changes in terminology over time have negatively influenced the understandings of palliative care in that definitions have grown more diverse, and there now exists a plethora of overlapping terms with different meanings.

Similarly to palliative care, many definitions of public health exist. Possibly one of the older, yet enduring definitions originates from Winslow who described public health as,

the science and art of preventing disease, prolonging life and promoting physical health and efficiency through organised community efforts for sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, the organisation of medical and nursing service for the early diagnosis and preventive treatment of disease, and the development of social machinery which will ensure to every individual in the community a standard of living adequate for the maintenance of health.⁵

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A different take on public health was brought about by the Ottawa charter in 1986.⁶ The charter heralded what is known as the *new public health*, or *health promotion*. This was a movement away from a narrow bio-medical model towards a broader conceptualization of well-being that acknowledges the influence of the person and their social context.⁷ In general terms, health promotion encompasses a range of interventions that seek to modify behaviour and the environment in order to improve health.⁸

It is therefore hardly surprising that the public health approach to palliative care (PHAPC) which encompasses the ideas and concepts of these two broad, evolving disciplines, poses some challenges for theoretical clarity. Indeed, recently in the editorial for a special edition of articles on community engagement in the journal *Progress in Palliative Care*, Rumbold and Aoun⁹ acknowledge the 'breadth and ambiguity of public health frameworks' and Clark¹⁰ has also highlighted this lack of clarity.

A public health approach to palliative care, or the linking of the two disciplines has been made in a number of ways. Dzingina and Higginson¹¹ state that the first reference to palliative care being identified with public health was in a paper by Wilkes¹² published in *The Lancet* in 1984. This paper highlighted the fact that chronic conditions were responsible for more deaths than cancer and on this basis argued that palliative care needs to be more integrated into public health services.¹² Clark¹³ identifies the first real linking of palliative care to public health as having occurred within the WHO, and in particular in the work of one time Chief of Cancer, Jan Stjernsward. Either way, palliative care is now commonly referred to as a public health concern by the WHO who often frame this association in the language of their Public Health Model which aims to integrate palliative care into all levels of society. Policy, drug availability, education, and implementation are key elements of this strategy.¹⁴

A different, but equally important, connection between palliative care and public health is that made by sociologist Allan Kellehear. He proposes a public health model of palliative care that aligns the principles of palliative care with those of health promotion as outlined in the Ottawa Charter.¹⁵ These health-promoting ideas are now well known in Australia and the UK in particular. Kellehear is closely associated with the Public Health and Palliative Care International Association (PHPCIA) which defines a public health approach to palliative care as,

one that views the community as an equal partner in the long and complex task of providing quality health care at the end of life. Just as

health, according to WHO, is 'everyone's responsibility' so too is death, dying, loss and care.¹⁶

While this definition acknowledges the social aspect of the WHO's take on health, it makes no overt reference to WHO's public health strategy for palliative care.

These variations in theoretical frameworks for understanding the interface between public health and palliative care form the backdrop and impetus for this review of the current research literature. The aim of the review was to identify studies that explicitly claim to support a PHAPC in order to explore variations in theoretical understandings of what such an approach actually constitutes.

Methods

The review follows the framework put forward by Whittemore and Knafl¹⁷ for rigorous integrative literature reviews, allowing for the inclusion of qualitative and quantitative data.

The search was carried out by C.D. with the help of a specialist librarian at Auckland University during December 2015. The databases Cinhal, Medline and Psychinfo were searched using combinations of the following search terms: palliative care, hospice, terminal care, end-of-life care, public health, health promotion, community engagement, community development, compassionate communities, social capital, and social networking. The search was limited to empirical studies, published between 2005 and 2015, written in English, and that expressly acknowledged their study as sitting within the framework of a public health or health-promoting approach to palliative care.

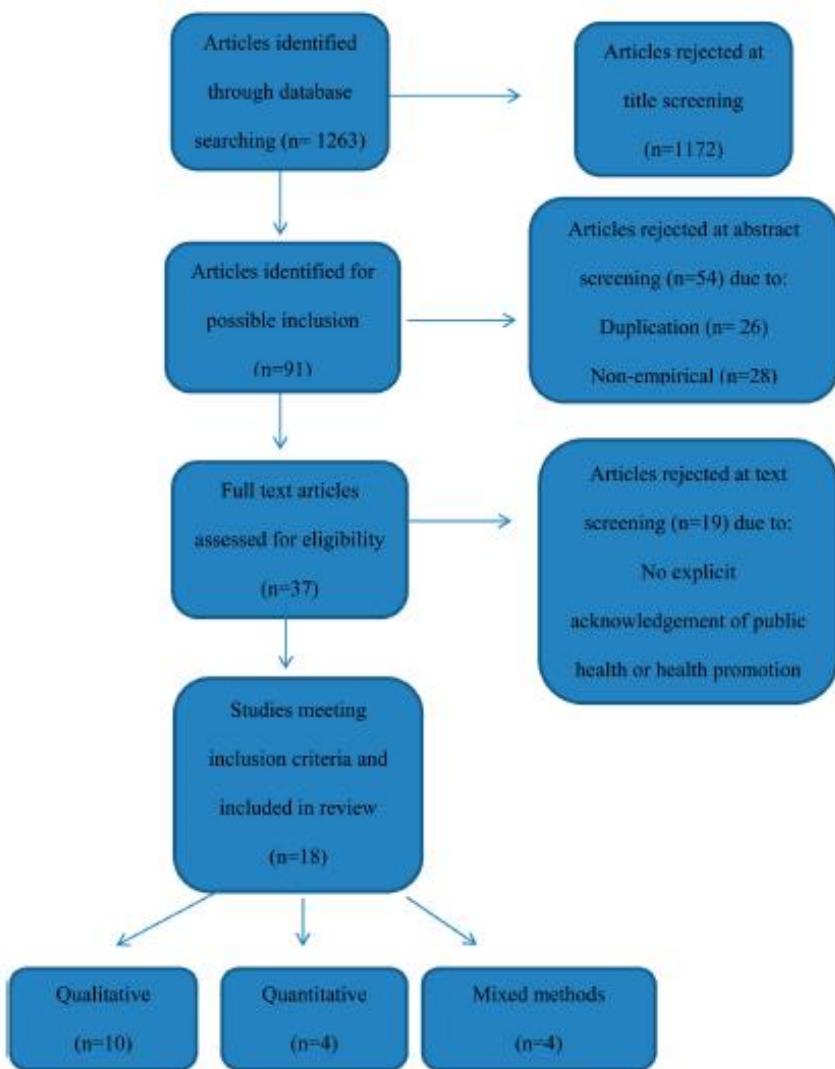
Details of the selection process are outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) chart¹⁸ (Fig. 1).

Data evaluation stage

Integrative literature reviews do not lend themselves to evaluating the quality of data, due to the challenge of applying uniform quality criteria to such a diversity of research designs.¹⁷ Furthermore, the focus of this review was not the research findings, but the conceptual framework adopted and therefore quality was less relevant than in a traditional systematic review. Therefore, the studies included in the review were not assessed for quality before analysis.

Data analysis stage

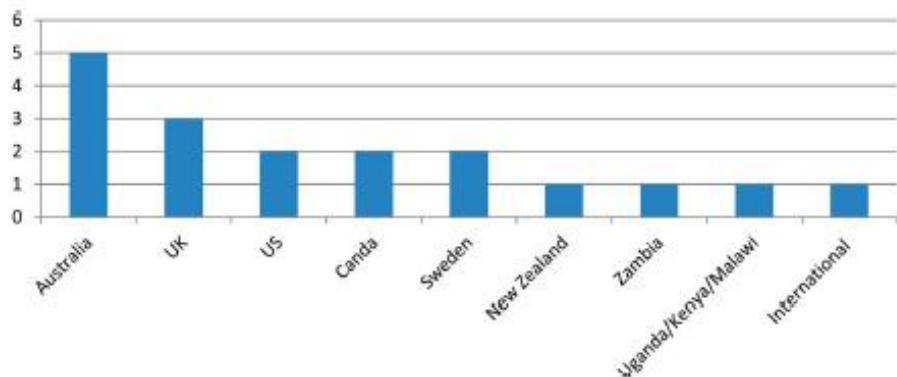
The analysis of the data from the literature took place over three stages, and was based on the flexible method for thematic analysis suggested by Braun and Clarke.¹⁹ First, to aid with data familiarization a basic literature chart was developed to sort and organize the data, and then a thorough reading of each study was undertaken. A table summarizing the included studies may be found in the appendix. Second the data were coded

**Figure 1** PRISMA flow diagram detailing selection of articles

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based upon the words the authors associated with a PHAPC. Braun and Clarke¹⁹ refer to this as, 'coding to identify a particular feature of the data set'. In

order to do this, text that included the search terms and their surrounding context were extracted. These data extracts were then used to generate codes.

**Figure 2** Chart showing the geographical origins of included studies

Third, the codes were analysed for patterns in content or meaning, as suggested by Saldana.²⁰ These were grouped together into bigger sub-themes and themes. Themes were reviewed by both C.D. and M.G. until consensus was reached.

Results

Of the 18 articles identified by the search, four were mixed methods, five were quantitative, and nine were qualitative. Of the mixed methods studies, two were evaluation studies. The dominant method for data collection in the qualitative studies was interviews ($n = 7$). Among the quantitative studies, the use of surveys ($n = 4$) was most prevalent.

The geographical origins of the included studies is displayed in Figure 2. Social or caring networks were the subject of three of the studies. Bereavement, place of death, and public awareness were each the subject of two studies. The remaining topics were each the subject of one study: service delivery through community groups, service delivery through home care services, palliative care professionals, the uptake of a PHAPC, education, opioid availability, and existential issues.

Three overarching themes were created which relate to how a PHAPC was conceptualized by the authors of the studies (Fig. 3). These are now discussed:

Theme 1 – Health-promotion approach

This theme, namely a *health-promotion approach* captures how 12^{21–32} of the articles articulated a PHAPC, and this was the dominant theme in the literature. Eleven of these studies used the actual words, ‘health promotion’ to frame their study, and the one²⁷ study that did not, referenced the works of

Kellehear on health promotion as the theoretical underpinning of a PHAPC.

Three sub-themes were identified within this theme. The first was that of *community*. Many of these studies referred to the importance of community in their descriptions of a PHAPC. Four^{21,24,25,29} studies promoted the use of community as providers of care over the further development of formal services. Horsfall *et al.*²³ advocated for a move away from traditional health promotion, where community members might be the passive recipients of education, to a more active model where they are agents of care provision through informal networks. Likewise, Paul and Sallnow³⁰ argue for a move away from traditional public health methods towards a community engagement approach where the community is active in their own care. The use and growth of social networks in end-of-life care was seen as a demonstration of a community development model in the study by Leonard *et al.*²⁴ In all the studies, the term ‘community’ appeared to refer to people or places or both. While Mills *et al.*,²⁹ Leonard *et al.*,²⁴ and Horsfall *et al.*²³ all acknowledged the challenge of actually defining community, only Mills *et al.*²⁹ stated their particular definition in the context of their study. They write, ‘in this context, communities are represented by existing or potential networks of individuals and groups that either share or have the potential to share common concerns or goals’²⁹ (p. 219).

The second sub-theme identified was *assets*. The codes that informed the development of this sub-theme all described asset-based rather than deficit-based thinking. For example, in Benzein and Savemans²² descriptions of health-promoting conversations, the authors highlighted the need for acknowledging resources and wellness as opposed to deficits and illness. Three^{23–25} of these studies, all Australian, were concerned with social capital, which Lewis *et al.* describe as a ‘relational resource’²⁵ (p. 2). It was reasoned that social capital in the form of caring networks furthers public good by meeting wider needs,²³ contributes towards a de-medicalization of death,²⁴ helps care for disadvantaged populations, and adds to greater sustainability.²⁵ One³² study considered health promotion as an empowering model that decreased dependence on statutory services.

The third sub-theme had to do with the described *benefits* of a health-promotion approach. The background to Lindqvist and Tishelman’s²⁶ study describes how using opportunities to reflect on death and dying helps to break down taboos and increase awareness of end of life issues. These two benefits, along with improving access to palliative care, are identified as the outcomes of a PHAPC by McIlpatrick *et al.*²⁷ Paul and Sallnow³⁰ also cite examples of how community engagement methods have improved access to

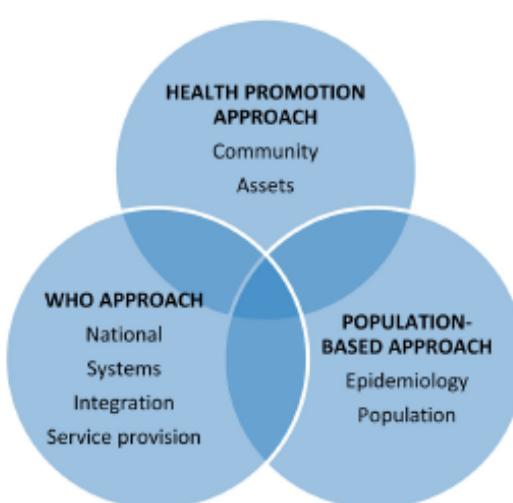


Figure 3 Themes: the articulation of a PHAPC in the literature

palliative care services. Two studies^{30,31} mentioned holistic care as an intended outcome of health-promoting palliative care. Other benefits mentioned included achieving a 'good death'³¹ and positive changes in knowledge, attitudes, and behaviours.²⁸ Additional benefits of recognizing and developing social capital have been described in the sub-theme *assets*.

Theme 2 – World Health Organisation (WHO) approach

All three studies^{33–35} that contributed codes towards this theme expressly acknowledge the use of WHO guiding documents and strategies related to palliative care. Two^{34,35} of the articles reported evaluation studies using mixed methods, and were based in African countries. The other study³³ was an international study that used epidemiological methods to determine variables that might be associated with opioid availability. All three studies considered their topic from a national perspective and all three spoke of integration into the existing public health systems as being a goal to strive towards. Integration was also spoken of in terms of palliative care being incorporated into national policy.³⁴ Two studies^{34,35} made reference to the national burden of palliative needs, and also articulated the need for better reach of service provision. Equitable service provision and the development of programmes were described by Grant *et al.*³⁴ as being necessary and important. In Logies' study,³⁵ the issue of funding and sustainability was raised in terms of palliative care service provision.

One study²⁷ fitted into both themes of the *WHO approach* and *Health-promotion approach*. This study advocated for incorporating elements from both paradigms, arguing, 'the need for a parallel approach ensuring that palliative care is more integrated into health service systems alongside a continued public health approach to palliative care in order to eradicate social taboos and ensure services are sought out when required'²⁷ (p. 6). This was the only study that acknowledged dichotomous models, and from this extract it is implied that one approach is socially orientated and the other systems orientated.

Theme 3 – Population-based approach

Three studies^{36–38} did not fit comfortably into either of the first two themes. Of these three studies, two made very limited reference to the WHO strategic documents related to palliative care (in comparison to those allocated to the *WHO approach* theme), and one made no mention of the WHO at all. Neither did these three studies fit into the first theme *health-promotion approach* since they made no reference to health promotion. Thus the third theme, a *population-based approach* was generated using the codes from these three articles. A valuing of population

level data was evident in all three studies; one³⁸ was a population-based survey, one³⁷ expressly advocated a population-based approach, and the third³⁶ was a pilot survey that recommended the results be tested in a larger population-based study. Foundational elements of traditional public health namely epidemiology, research and policy are described by Lupu *et al.*³⁷ as the tools of public health necessary for a PHAPC. In the study by Wilson *et al.*³⁸ which considered public preferences regarding the place for end-of-life care, epidemiological concepts were considered and a good home death was described as the desirable outcome of public health interventions at the end of life. The developments of service provision options, as well as the development of community capacity, are acknowledged in the study by Aoun *et al.*³⁶ This study also recognized the importance of cost savings and equity in allocating resources in the context of a public health model.

Discussion

The three themes identified in this literature review may be thought of as three different paradigms of a PHAPC. The *health-promotion approach* is the dominant articulation of a PHAPC in the current literature. Noteworthy is the prevalence of the term *social capital* in the articles that contributed to the *health-promotion approach* theme. Social capital is a concept growing in popularity within the social science literature.³⁹ It has also been proposed as a potential model to support well-being in palliative care.⁴⁰ The term neatly covers a range of beneficial social links within groups, between groups and across hierarchies. However, as a concept, it has been criticized on a number of points including its' lack of clear definition; the simplistic use of the term to cover an extensive range of phenomena; its inability to recognize cross-cutting links of gender, ethnicity and class; and the implied meaning of the word 'capital' being that it only generates positive outcomes.³⁹ These criticisms have not been addressed within the palliative care literature, indicating a need for palliative care to more fully engage with literature in other disciplines where the theoretical foundations of key concepts drawn upon in health-promoting palliative care have been widely critiqued.

The second paradigm identified by the review was the *WHO approach* which reflects the ideas of the WHO Public Health Strategy for Palliative Care.¹⁴ As mentioned earlier, this strategy highlights four essential pillars for improving and integrating palliative services into country health systems, namely policy, drug availability, education, and implementation. These features, specifically integration, a health systems focus, the importance of policy and opioid availability were clearly associated with a PHAPC in the three studies linked to this theme. It

appeared that taking a public health approach meant measuring palliative care success in terms of how well integrated it was into the mainstream health systems, how significantly it was reflected in policy, and how widely available opioids were.

These first two paradigms appear to have different goals. Those studies reflecting the *WHO approach* are concerned with integrating palliative care into health systems, at country level predominantly, and therefore reach and service provision are core concerns. The studies linked to a *health-promotion approach* talk much about social empowerment and the de-medicalization of death, and this seemingly at a community level. However, while this does show different emphases, it cannot be said that these two themes are mutually exclusive, because arguably the goals of one would support the goals of the other being achieved. Community empowerment and mobilization would certainly improve reach, as has been demonstrated elsewhere.⁴¹ Also, it must be acknowledged, that although not made clear in the studies included in this review, social participation and community ownership is unambiguously upheld in the WHO Public Health Strategy for Palliative Care and therefore this is shared ground between these two approaches.

The third way in which palliative care issues were associated with public health in the literature was simply from a population perspective, often relying on the science of epidemiology for evidence. This paradigm may be described as a *population-based approach*. Public health has been called a population science in that it is concerned with issues affecting groups of people rather than individuals. Perhaps a population perspective aligns palliative care issues with public health simply because they affect a significant number of people. The studies that reflected this conceptualization made no explicit link to health promotion or the Ottawa charter, and none to the WHO public health strategy for palliative care. Again, this does not mean that this approach sits in isolation of the first two. Indeed a population approach and the use of epidemiology may be employed and upheld by proponents of all three paradigms.

Limitations

While rigorous and systematic methods were used to conduct this review, certain limitations must be acknowledged. Owing to resource constraints we were only able to include papers written in English and the search was limited to the published literature contained in the included databases. It is also acknowledged that the breadth of the topics under consideration might have limited the sensitivity of the search.

Conclusion

This integrative literature review makes an important contribution to current understandings of the integration of a public health approach into palliative care research. We identified 18 research papers that expressly identified their studies as nested within a PHAPC. A thematic analysis of the texts has shown that a PHAPC was conceptualized by the authors of these studies in three different ways. The dominant theme was that of a *health-promotion approach*, the other two less dominant themes were labelled a *WHO approach* and a *population-based approach*. It must be acknowledged that these three themes share significant common ground which in itself can add to the confusion. In addition, key concepts adopted from the discipline of public health, notably 'community' and 'social capital' are rarely defined, pointing to an urgent need for further engagement by palliative care researchers with the theoretical underpinnings of public health approaches. The need to pin down these understandings is important not only for the sake of clarity, but also for the future growth and application of these ideas within palliative care. In light of this, we recommend that authors make clear which PHAPC they are drawing on to inform their research.

Disclaimer statements

Contributors C.D. is the main author and takes responsibility for the content of this article. All data collection and analysis was guided by M.G. and completed by C.D. The manuscript was critically revised by both authors. This study forms a part of a master's thesis for which M.G. is supervisor.

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Conflicts of interest The authors declare no conflicts of interest.

Ethics approval Ethics approval was not deemed necessary for this literature review, however the thesis of which forms a part has been approved by the University of Auckland Human Participants Ethics Committee reference number 016999.

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Appendix

Table 1 Literature chart of all included studies

| Author, Year, Country | Aim of study | Participants/sample | Study design and method | Key findings | Link to PHAPC | Theme |
|--|---|--|--|--|--|---------------------------|
| Aoun et al., 2014 Australia | To pilot test a survey associated with a theoretical public health model for bereavement support | 23 clients from three funeral providers 6–24 months post bereavement | Quantitative and qualitative data from a postal survey | Empirical support for the survey and the model was gained | The bereavement model proposed here is population-based – different levels of interventions target different populations | Population-based approach |
| Bellamy et al., 2014 New Zealand | To explore older people experiences around bereavement support | 28 bereaved older adults from three different regions | Qualitative telephone interviews | Family and friends play a pivotal supportive role in bereavement, as do community-based organizations. | The use of existing community supports in bereavement care is highlighted and there is explicit linking to the work of Kellehear | Health-promotion approach |
| Benzain and Savema, 2008 Sweden | To describe couples experiences of taking part in nurse-initiated health-promoting conversations about existential issues | Six couples, where one of them had advanced cancer and was receiving care from a palliative care home team | Qualitative semi-structured interviews | The need for formal bereavement services was questioned by the majority of participants. | Health-promotion in palliative care was central to this study and explicitly referred to | Health-promotion approach |
| Gillson et al., 2013 International | To examine the influence of governments and health systems on opioid availability | 177 countries consumption of opioids in relation to other variables such as human development index, palliative care infrastructure, health system resources and expenditure | Quantitative multivariate regression | Few predictor variables can explain opioid consumption, although a high human development index was associated with higher opioid consumption | Specific reference is made to the WHO public health approach to developing palliative care. Opioid availability is a very pillar of the WHO strategy | WHO approach |
| Grant et al., 2011 Uganda, Kenya, Malawi | To describe local perspectives on the impact of three community-based palliative care interventions | 33 patients, 27 family carers, 36 staff, 25 volunteers and 29 community leaders Uganda, Kenya, Malawi | Evaluation study using interviews, observations and routine statistical data | Holistic care was delivered effectively and 'good' deaths were achieved at home. Mobile phones facilitated access to clinical and social support networks | Key points in the discussion included access to oral morphine, and the impact of health systems on programme delivery. The conclusion recommended a public health approach to more effectively meet national needs | WHO approach |
| Horsfall et al., 2012 Australia | Nature, quality and effect of social networks i.e. how they function | 94 carers representing 17 caring networks in New South Wales | Qualitative creative methods (photo voice, network mapping and interviews) | Carers can successfully mobilise informal networks of supports to care for the dying at home | Social networks were described in terms of social models of care, social capital and community development. The background to the study referenced the work of Rumbold and Kellehear | Health-promotion approach |
| Leonard et al., 2015 Australia | To analyse the caring networks of people with a terminal illness and identify changes over the time of caring | 77 people (in nine focus groups) from the caring networks of nine patients | Qualitative and quantitative (Social network mapping in focus groups) | Social networks were shown to increase in size, and the ties between members to strengthen over time. Core and peripheral networks were identified, and there was a diverse contribution to care | End of life caring was articulated as contributing towards social capital, and explicit links were made to Kellehear, community participation and development | Health-promotion approach |

| | | | | | |
|--|--|---|---|--|---|
| Lewis et al., 2014 Australia | To explore the nature of caring networks in lower socioeconomic populations | 16 patients and six informal carers in Western Sydney | Qualitative semi-structured interviews | Identified networks were mostly inadequate to meet needs for care | Health-promotion approach |
| Lindqvist & Tishelman, 2015 Sweden/International | To explore the preferences for the surroundings in which death takes place | Visitors to a museum exhibition yielded 512 responses from 46 countries | Qualitative Questionnaire Single question, open-ended | Eight categories of preferred death surroundings are identified: familiar death, larger than life death, lone death, mediated death, calm and peaceful death, sensuous death, green death, distanced death dying | Health-promoting palliative care was explicitly acknowledged as the framework for this study, and the ambition was to promote 'public awareness' around death and dying |
| Logie, 2012 Zambia | To evaluate the implementation of an advocacy strategy to improve palliative care in Zambia | Eight palliative care organizations | Evaluation study Multiple methods (desk surveys, interviews, field trips) | The four pillars of WHO's public health strategy are vital to success. Ongoing financial support is needed to maintain palliative care infrastructure | The initiative under evaluation aimed to achieve country level improvements in access to palliative care, explicitly based upon the WHO palliative care public health approach to palliative care is explicitly mentioned, and is defined as a population-based view' |
| Lupu et al., 2013 USA | To quantify the courses available that teach palliative care from a public health perspective | Schools of Public Health in the USA | Quantitative Survey of the web | Only six out of 49 schools included palliative care content in their curricula | A public health approach to palliative care is explicitly mentioned, and is defined as a population-based view' |
| McIlvanick et al., 2013 Ireland | To establish current awareness and attitudes of palliative care among the general public | 600 responses from members of the public | Quantitative Cross-sectional survey Structured questionnaire | Poor awareness of palliative care was found, especially among those with no previous exposure to hospice services | The study makes explicit links to a public health palliative care or health-promoting palliative care, referencing the work of Kellehear |
| McIlvanick et al., 2014 Ireland | To explore public perceptions of palliative care in light of health-promoting palliative care requiring more public ownership | 50 members of a community scheme in Northern Ireland | Qualitative semi-structured telephone interviews | Experience generates understanding and targeted educational strategies are required | Specific reference is made to Kellehear's health-promoting palliative care, and how low levels of public awareness are a challenge to the goals of a PHAPC |
| Mills et al., 2015 Australia | To explore community-based activities around end of life care that might link in with the philosophy of health-promoting palliative care | 10 representatives from eight local community groups with an interest in EOL issues in the Australian Capital Territory | Qualitative in depth semi-structures interviews and field notes | Themes identified from this study were practical support, respect and responsiveness, connection and empowerment. These were especially evident in groups where normalization was promoted | It was clearly articulated that this study was concerned with health-promoting palliative care and building community capacity in end-of-life care |
| Paul and Sallnow, 2013 U.K. | To scope if the public health approach to EOL care is a priority for UK hospices | 146 services from four UK countries | Quantitative (one open-ended question) Online survey | A public health approach to palliative care is a priority for the majority of UK hospices, and a range of work is being undertaken in this area | This study was explicitly about exploring the uptake of the public health approach to palliative care in the U.K. This approach was seen as synonymous with the terms compassion, communities, and health-promoting palliative care |

Continued

Table 1 Continued
Appendix

| Author, Year, Country | Aim of study | Participants /sample | Study design and method | Key findings | Link to PHAPC | Theme |
|-------------------------------|---|--|---|--|---|---------------------------|
| Rizzi, 2014 U.S. | To determine what professionals think about their work, and how does this thinking shape their practice | 12 hospice professionals from four disciplines and different organizations | Qualitative in-depth interviews | Promoting a good death was the overarching theme | The conceptual framework for this study made specific mention of the Ottawa charter and discussed the links between health promotion and palliative care | Health-promotion approach |
| Stajduhar et al., 2011 Canada | To examine the interpretation of family empowerment by home care services | 13 leaders from three health care agencies in British Columbia | Qualitative in-depth semi-structured interviews | Empowerment was seen as the long term goal of client/family self-care | Empowerment was articulated as a principle of health promotion. The work of Kellehear was referenced and specific mention of health-promoting palliative care | Health-promotion approach |
| Wilson et al., 2013 Canada | To determine public preferences for final days of life | 1203 adults living in Alberta sample | Quantitative survey by telephone | Home is the preferred place for end-of-life care for most people living in Alberta | This study was framed as taking a 'public health perspective' on end-of-life care. Importance was placed on gaining a representative population-based sample | Population-based approach |

APPENDIX 9 – Manuscript of thesis findings

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The status of a public health approach to palliative care at New Zealand hospices.

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Background: There is growing international support for a public health approach to palliative care; however, the status of the movement in the New Zealand context is unknown.

Aim: To explore the uptake, nature and understandings of a public health approach to palliative care by hospices in New Zealand.

Methods: A mixed method study using a convergent parallel design was conducted. In phase one quantitative data were collected using an online survey of hospice leaders, and in phase two qualitative data were generated from semi-structured telephone interviews with a sub-sample of phase one participants. Data from the survey were analysed using appropriate statistical techniques. Transcripts of the telephone interviews were analysed using thematic analysis. The findings from each phase were then triangulated to check for congruency.

Sample: Fifteen leaders (12 chief executive officers, and three senior managers) at New Zealand hospices participated in the online survey, representing a response rate of 54%. Ten of these participants took part in a semi-structured telephone interview.

Results: Analysis of the quantitative results confirmed that a public health approach to palliative care was a current priority at 60% of New Zealand hospices. However, both phases of the study demonstrated that community engagement, one of the chief out-workings of a public health approach to palliative care, was incompletely understood and practiced. Furthermore, the qualitative results showed that, while this approach is supported, there are significant barriers to implementation, including paternalism, resource constraints, adequate evaluation, and incomplete understanding of key concepts such as social networking and community engagement

Conclusion: This study is the first to explore the extent to which a public health approach to palliative care is supported by hospices in New Zealand. The unique new findings show that there is need for the model to be recognised in policy. Related to practice, if the model is to be implemented to maximum benefit, further conceptual clarity of the key tenets is needed. In addition,

addressing the barriers to implementation identified by this study will need to be prioritised by hospice leadership.

Keywords: understandings, uptake, nature, support, scope, status, public health, palliative care.

Introduction

A public health approach to palliative care (PHAPC) necessarily adopts the tenets of both palliative care and health promotion. It takes the principles of health promotion and applies them to addressing the morbidities and mortalities associated with death, dying and loss.¹ The approach, which has been laid out in seminal works by Allan Kellehear,^{2,3,4} is defined by the Public Health and Palliative Care International Association (PHCIA) as follows.¹

A public health approach to palliative care is a health promotion approach to end of life care, one that views the community as an equal partner in the long and complex task of providing quality health care at the end of life. Just as health, according to WHO, is ‘everyone’s responsibility’ so too is death, dying, loss and care.

This approach requires a significant shift in the way hospices plan and provide care, away from a professional, service driven approach towards working in partnerships with communities.⁵ Indeed, the model places a strong emphasis on the important role that communities can play in end-of-life care, and has been described as an essentially social model.³

A PHAPC is steadily gaining support across the world with applications thereof well documented in the UK⁶, Australia⁷, India⁸, Sri Lanka, Thailand, and Indonesia.⁹ A recent systematic review of academic studies framed in a PHAPC perspective, found that the bulk of the literature originates from Australia and the UK.¹⁰ A scoping survey of UK palliative care services found this approach was prioritised by 60% of the respondents.¹¹ However, the status of a PHAPC in New Zealand is relatively unknown.

Therefore, given the growing importance of the approach elsewhere, this study aims to explore the understandings, uptake and nature of a PHAPC within hospices in New Zealand.

Method

This study adopted a pragmatic philosophy, using a mixed method approach. A convergent parallel design as outlined by Creswell & Plano Clark¹² was chosen. Phase one was an anonymous online survey of Chief Executive Officers at all New Zealand hospices with the exception of the hospice at which CD is currently employed (N=28). The survey tool chosen was the same used in a study of UK palliative care services in 2013¹¹, with minor adaptations to the NZ context. Categorical data were analysed using basic descriptive statistics¹³ and textual data using content analysis.¹⁴

Phase two involved conducting semi-structured telephone interviews. All those who responded to the online survey were offered the opportunity to take part in the interviews. Informed by the literature¹⁰ an interview guide was developed which probed understandings of the approach and key concepts. Interviews were transcribed, and analysed using thematic analysis as outlined by Braun and Clarke.¹⁵ Four themes were generated from the interview data, these were: Taking stock: current understandings of a public health approach to palliative care; Growing community engagement; New tools; and Recalibrating palliative care.

Careful consideration was given to enhancing rigour in the following ways: an audit trail of decision-making¹⁴; an acknowledgement of reflexivity in the qualitative phase¹⁶; debriefing through regular supervision; attention to the importance of response rates for generalisability¹⁷; and member checking of interview transcripts.¹⁸ Methodological triangulation¹⁹ was undertaken by comparing and integrating the findings from phase one and two in relation to the three parts of the

research question – the uptake, nature and understandings of a PHAPC. In all instances the findings demonstrated congruence.

Participants

Out of 28 hospices eligible to participate, 15 took part in the survey, representing a response rate 54%. According to Baruch's²⁰ comparative analysis of response rates in academic literature, this rate is well above the norm of 36% found in surveys of people in top management positions. Ten of the leaders who completed the online survey took part in further semi-structured telephone interviews. Characteristics of the participants and the hospices they represented are shown in Table 1 & 2 respectively.

(Insert Table 1 and Table 2 near here)

Findings

Understandings of a public health approach to palliative care

Participants in phase two reported that they found a PHAPC a difficult concept to understand. The elements of a PHAPC most commonly identified were education, community, a population perspective and health promotion. The self-reported influences on leader's thinking and understandings of a PHAPC were identified as being personal reading, work experience, the compassionate communities' movement in the UK, and influential academics and allied health professionals.

It's still a concept that is foreign for many of our staff...So what we're trying to do is...talking much more to staff, you know, 'this is how this (initiative) supports that (public health) approach', so that people can be enabled to understand it through examples.

#8

Understandings of community engagement, which is closely associated with a PHAPC, were also reflected in the qualitative data. Community was described in terms of people, places or both. Most of the leader's defined community as those people touched in some way by the hospice service, and two of these leaders specified these to be patients and families. Only three leaders had a wider view of community that included the public more generally. Participants also identified those groups that they felt were particularly difficult to engage with within their communities. These were Māori, ethnic minority groups, younger people and the primary health sector.

The community around the hospice tend to be those that have been touched by the hospice.

#12

The uptake of a public health approach to palliative care

Sixty percent (n=9) of survey participants reported that a PHAPC approach was a current priority at their hospice. Thirty-three percent (n=5) said that although it was not a current priority, it was likely to become one in the future. One respondent selected the option stating that it was not a priority due to a lack of resources. No leaders responded that a PHAPC was not within their remit.

The interview data confirmed support for a PHAPC, with the majority of participants saying it was the right direction for the future of hospices, and that public health and palliative care

complemented each other. Only two had never heard of a PHAPC, and prior to the interview had not even associated palliative care with public health.

Supporting a PHAPC necessitates adopting the new ideas associated with it. Participant's views and understandings of two of these new concepts, namely social networks and death cafes, were explored. The application of the social network model involves identifying and mobilising people's natural social supports.^{21,22,23,24} Most participants explicitly stated that they had no formal knowledge of the model and had not heard about it before. Others incorrectly described the model and therefore also displayed limited knowledge. Only two leaders were aware of the social network model, and described it correctly. Despite limited formal knowledge of this model, there was significant support among hospice leaders for the concept and some felt that they were already applying elements thereof at their hospices.

I haven't heard about that model, but actually that's something that we do as a matter of course here.

#6

Social isolation was identified as a challenge to applying a social network model, and most leaders agreed that this was a growing issue within their communities. Family carers, immigrants, and older people were thought to be at risk from social isolation. In this context, the issue of ageism was raised and the scope of hospice referral criteria questioned. A number of participants expressed doubts over the appropriateness and the availability of resources for hospices to provide support to isolated older people with no palliative care needs. Conversely it was raised that older people are, by virtue of their age, nearing the end of life and therefore do have palliative care needs.

For hospice, one thing that really, I think we have to go back and look at our referral criteria because I think that we are quite ageist, and I often think well, okay, this person may not need specialist palliative care, but they need a whole lot of other things that hospice can provide, like volunteers.

#11

The second new concept explored was that of death cafes. These are used as a means of engaging the wider community in conversations around death and dying. A few participants were supportive of the idea and had found them to be useful in breaking down barriers to talking about these topics. However, most of the participants were uncertain about the value of death cafes. There was a distinct dislike of the terminology ‘death cafe’. Most felt they would wait and see if the idea had success elsewhere.

Hate the name. That's a personal thing...I find it an interesting concept...I'm not sure that death cafes are the answer. They might be part of the answer, you know?

#14

Finally, the qualitative data revealed some of the perceived implications of supporting a PHAPC. In light of possibly adopting this new approach, participants contemplated the place of existing models - in particular the medical model of death and the specialty model of palliative care. The bulk of participants felt that the existing model of dealing with death within the health sector was indeed over-medicalised and resulted in negative consequences. These included de-skilling the community; fostering paternalism within health care; a lack of preparation for death and bereavement; and a focus on aggressive treatment. A smaller number of participants were wary of supporting the notion that death had been ‘over-medicalised’ because they felt that it undervalued

the contribution the existing medical model had made towards holistic palliative care. Similarly, there were mixed feelings about the specialty model of palliative care. Some participants said that this model was not sustainable, that it fostered a lack of preparation upstream, exclusivity and resulted in discomfort with end-of-life issues in primary settings. Conversely others were adamant about the need to retain the speciality element of palliative care.

I think our care has in many ways become more medicalised, although sometimes I think we're a little unfair on ourselves... The medical model – it's still a very powerful model.

#11

The nature of a public health approach to palliative care

The interview data showed that most participants operationalised their support for a PHAPC through community engagement activities. Favoured community engagement activities identified by the survey respondents are shown in Figure 1.

(Insert Figure 1 near here).

When survey respondents were asked to describe their community engagement activities in greater detail, content analysis enabled the activities to be categorised according to the spectrum of community engagement in end-of-life care outlined by Sallnow & Paul.²⁵ Of the 55 activities described, 87% (n=48) activities were classified as falling at the weaker end of the community engagement spectrum; in other words the aim of most of the activities was to *inform* or *consult* with the community. A further 12.7% (n=7) of the activities were classed as being a *co-production* which sits midway along the spectrum. No activities could be classed as being *collaborating* or

empowering which are those activities thought to be most powerful and are seated at the far right of the spectrum. See Figure 2.

(Insert Figure 2 near here).

Qualitative data reflected similar findings in that community engagement activities could be grouped into two broad categories - *less* and *more* powerful community engagement (again using the guidelines given by Sallnow and Paul²⁵). Most of the activities were allocated to the *less* powerful category because of their focus on service provision for the benefit of patients and families. Many activities in this category could be described as social marketing of the hospice service. Data related to volunteers, education and partnerships all centred on service delivery or fundraising.

We do promotion of our services at events – we might have stalls, shops, radio advertising.

It's usually advertising the shop or advertising hospice in general.

#14

Fewer activities were allocated to the *more* powerful category. Activities allocated here had a focus on working with the wider community, with the goal of increasing the capacity of the community, and partnerships were more about sharing ownership and responsibility for decision-making.

It's all about enhancing community resilience, so people feel better prepared across all realms to cope with death and dying and grief and loss.

#8

Data from phase one of the study shed some light on the respondent's rationale for doing community engagement, respondents identified activities they felt were most successful and justified these choices. Content analysis of their reasoning showed that 14.2% (n=2) of leaders thought activities were successful because they benefitted the wider community in some way; 14.2% (n=2) because the activities were mutually beneficial for the hospice and the community; and 35.7% (n=5) because they were primarily beneficial to the hospice service.

Finally, a number of barriers and enablers to community engagement were identified in phase two of the study. Barriers included a lack of resources, a lack of appreciation of cultural differences, procrastination, not having a systematic plan and simply having other priorities. Conceptual difficulties around fully understanding the place of community engagement within a PHAPC were also raised. Public insight and attitudes towards death and dying such as death denial, stoic attitudes and misconceptions about hospice were noted barriers. Funding contracts were seen as restricting due to challenges with how to measure or report community engagement activities. Lastly, systemic paternalism on the part of health professionals was recognised as a challenge to developing a community engagement approach to end of life care.

Right from the beginning when we first organised workshops to bring people together, we were told that they (the health care professionals) were the experts and we didn't know what we were talking about, so leave it alone.

#4

Enablers of community engagement were identified as being pro-active, having a good reputation in the community, and having a staff that reflected the ethnic make-up of the local community. The space around bereavement was recognised as a largely untapped opportunity to engage.

Why aren't we thinking in this way? In terms of how bereavement might affect our communities and how we could then influence the bigger picture, the whole death and dying thing, through that.

#12

Discussion

This study provides new insight into the status of a PHAPC at hospices in New Zealand.

Participants noted that a PHAPC is a challenging concept to grasp. The literature confirms this and identifies a number of factors that make understanding the approach complex. Firstly, a PHAPC represents a novel model for palliative care - a more social approach.^{1,3,5} Secondly, the approach comprises of a combination of ideas from two broad and evolving disciplines – those being palliative care and public health.^{26,27,28,29} Thirdly, a number of public health frameworks for palliative care exist.^{5,10} Finally, there is a surfeit of terms associated with a PHAPC¹¹ which can be difficult to assimilate.

PHAPC is inextricably linked with community engagement.²⁵ However, this study supports findings elsewhere that community engagement is not outworked to its' fullest potential⁵, which brings into question the depth of understanding around the concept. Indeed, much of work described as community engagement is actually for the benefit of the service, rather than the benefit of the wider community.^{5,25}

Quantitative data from this study has established that a PHAPC is a current priority in 60% of the sample of hospices in New Zealand. These results are very similar to those obtained from the same

survey applied to UK palliative care services in 2013.¹¹ While UK policies around end-of-life care have recognised elements of a PHAPC for some time^{31,32}, currently no New Zealand national strategic documents for palliative care explicitly acknowledge a public health approach.

Participants identified that one of the key obstacles to taking up a PHAPC in the form of community engagement in end of life care was a lack of resources. This was also reported by the respondents in the UK survey¹¹ and more recently Herrera has identified this as an important challenge for implementing compassionate communities.³³ Current funding for hospices in New Zealand is driven by service provision.³⁴ Recognising and evidencing the ‘softer’ results stemming from community engagement activities was raised in this study as a barrier. Certainly, encouragement and guidance for measuring the impact of a PHAPC has been underscored in recent literature.^{5,35,36}

Another important obstacle raised in this study is paternalism. This issue has been highlighted by Rosenberg, Mills & Rumbold.⁵ Despite the positive effect of community action having been demonstrated³⁶, professional services often adopt a needs or deficit-based view of the community, rather than an assets-based view that acknowledges the natural strengths that people have within themselves and their social networks.³⁷

For the participants in this study, supporting a PHAPC meant engaging with some new ideas. One of these was the social networking model. A number of challenges for implementing this model were raised. One of these was identified as social isolation, particularly among older people. Interestingly, the issue of ageism in hospices was raised in this study in the context of widening referral criteria to accommodate the social needs of older people at the end of life. While there is

certainly evidence that ageism is a problem within health care in general,^{38,39} Lloyd suggests that in the hospice context the evidence points more to the challenge of recognising palliative need rather than ageism per se.⁴⁰

The second new concept that was raised in this study was Death cafes. These are social gatherings where conversations around end-of-life issues are facilitated.⁴¹ The official Death Cafe website lists that 31 death cafes have taken place in New Zealand, 157 in Australia and 678 in the UK.⁴² Despite growing support for the death cafe movement, most of the participants in this study were uncertain about their value, showing particular aversion to the terminology. Arguably, it is precisely this discomfort that death cafes seek to address. No literature exploring health care professionals' attitudes towards death cafes could be found.

Discussing the uptake of a PHAPC kindled introspection among study participants of the models currently employed by palliative care. The professionalisation of death has been identified in the literature and is widely accepted as one of the motivations for the PHAPC.⁵ While a number of hospice leaders agreed that a medical model had led to negative consequences for communities in that they were de-skilled in the issues of death and dying, there was also strong support for the value and contribution of the medical model to date. Similarly, palliative care being a specialty raised diverse feelings. This is not surprising as the recognition of palliative medicine as a specialty has been widely debated since it came about in the UK in 1987, and in New Zealand in 2001.⁴³ It is important to note that the chief proponents of a PHAPC have consistently maintained that adopting a social model does not mean excluding the medical model, but rather acknowledging the important contribution of both.²²

In this study, the nature of a PHAPC in New Zealand is most acutely revealed in the findings related to community engagement. Results from both phases have shown that the bulk of activities carried out by New Zealand hospices under the umbrella of community engagement fall at the weaker end of the community engagement spectrum. This trend to favour activities on the left of the spectrum (inform and consult-type activities) has been noted by proponents of the approach and is not unique to New Zealand.⁵

Strengths of the study

This study is the first to explore a PHAPC in New Zealand and the first determine support for the approach within local hospices. It therefore adds weight to the call for a PHAPC to be prioritised in the strategic planning of end-of-life care locally, regionally and nationally.

The use of a mixed method approach adds confidence in the study findings in that the results from the quantitative and qualitative phases are congruent in the ideas and trends they identified.

Limitations of the study

With regards the quantitative phase of the study, external validity was limited by the response rate, and therefore while the study has highlighted trends it does not speak to all the hospice services in New Zealand. As with all surveys, the findings are limited to the specific time frame of the study.

Related to the qualitative phase of the study, it is possible that those with a particular interest in a PHAPC were those who chose to participate in the interviews. This may have introduced a bias in

their knowledge or support for the approach. In addition, the data may have been somewhat limited by the semi-structured nature of the interview schedule.

Conclusion

There is clear support for a PHAPC by hospice leaders in New Zealand, in that more than 90% of respondents to this study have either currently prioritised this approach or plan to do so in the future. This is the first study to confirm support for the approach and therefore it affirms the importance of including a PHAPC in policy and planning for the future of palliative care services in this country. In practice, a deeper understanding of a PHAPC, and community engagement in particular is needed if the model is to be applied meaningfully. Future research should contribute towards enhancing conceptual clarity, exploring some of the barriers and evidencing the outcomes of the approach.

Disclaimer statements

Contributors C.D is the main author and takes responsibility for the content of this article. All data collection and analysis was guided by M.G and completed by C.D. The manuscript was critically revised by both authors. This study presents the findings of a master's thesis for which M.G. is supervisor.

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Tables and Figures to be inserted into manuscript:

Table 1: Characteristics of the survey respondents

| | CEO | Other position of leadership | Unknown | Total |
|---------|-----|------------------------------|---------|-------|
| Male | 2 | 1 | | 3 |
| Female | 7 | 2 | | 9 |
| Unknown | | | 3 | 3 |
| Total | 9 | 3 | 3 | 15 |

Table 2: Characteristics of the hospices

| | Number of responses | Rural population | Urban population | Rural & Urban population | In-patient service | Home care Service | Day Hospice service |
|------------------------------|---------------------|------------------|------------------|--------------------------|--------------------|-------------------|---------------------|
| Hospices in the North Island | 12 | 2 | 3 | 7 | 10 | 12 | 9 |
| Hospice in the South Island | 3 | 0 | 0 | 3 | 2 | 2 | 1 |
| Total | 15 | 2 | 3 | 10 | 12 | 14 | 10 |

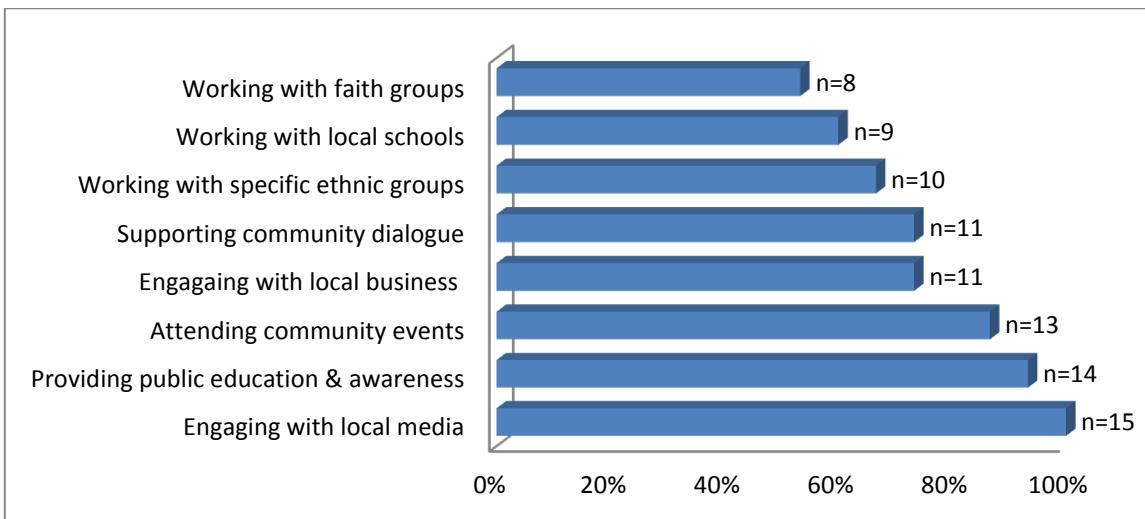


Figure 1: Bar chart showing the percentage of hospices carrying out selected community engagement activities

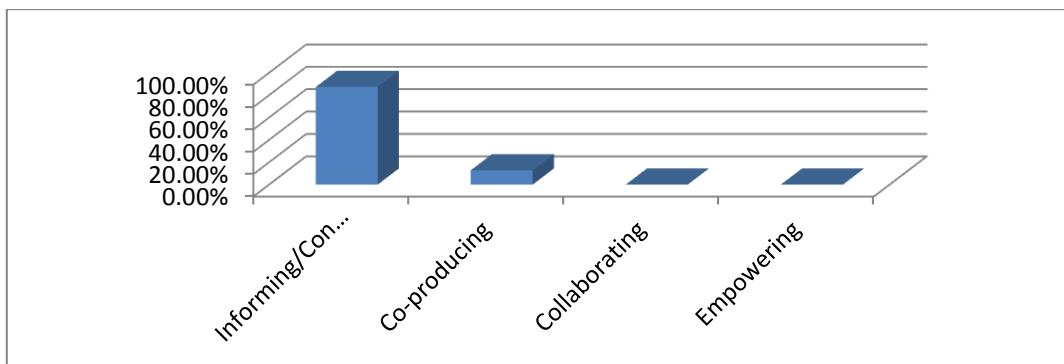


Figure 2: Graph showing the percentage of activities allocated to points on the community engagement spectrum

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