Implementation Science in Palliative Care: Recommendations for an Education Programme for Hospice Patients

A thesis presented in partial fulfilment of the requirements for the degree of

Master of Science

in

Psychology (Endorsement in Health Psychology)

at Massey University, Manawatu, New Zealand

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2023

Abstract

There are a variety of approaches that can be used to develop education programmes targeted towards palliative care patients, and many intervention approaches have been trialled both locally and internationally. However, as with many forms of research, there is a gap between evidence-based findings being published and these findings making it into professional practice approaches. Implementation Science is one approach that attempts to bridge the gap between research and practice. This research aimed to discover what both patients and staff members at a Hospice facility felt were effective approaches to use when creating a patient-centred palliative care programme. In-depth interviews with semi-structured, open-ended questions were conducted with participants, who were asked to share their views on palliative care education, what makes a suitable patient programme, how to meet the cultural needs of patients attending the programme, and how to effectively engage patients in the programme. The interviews were recorded, transcribed, and then analysed using thematic analysis. The interviews were then compared with evidence-based research to attempt to bridge the gap between research and practical applications. Themes such as addressing stigma, relationship dynamics, practical group considerations, and the complexities of carer inclusion emerged from the interview findings. Recommendations were then made about specific ways an education programme can be developed for palliative care patients, using an Implementation Science model to guide these recommendations in a practical way.

Acknowledgements

I would like to acknowledge the following people who supported me during my journey towards completing my thesis.

Firstly, thank you to Chris and Don, my supervisors, for their guidance, direction, support, and constructive feedback which has made me a better researcher and writer throughout this process.

To the Otago Community Hospice, thank you for letting me conduct my research at your service. To Denise, my on-site supervisor, I appreciated all your thoughts and advice, and the listening ear you always provided.

To the participants in this research – I couldn’t have done this without you all, and I thank you for your vulnerability, time, and valuable contributions. You are truly the voice of this research.

To my family, thank you for all your support throughout the year, and always being there for a laugh while I worked through the thesis.

Finally, to my partner Katherine. You were there through this whole process and I couldn’t have done this without your support. Thanks for always picking me up when I doubted myself, and for reassuring me when I needed it. I love you, always.

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List of Abbreviations

BHI: Brief Hope Intervention

CFIR: Consolidated Framework for Implementation Research

COPD: Chronic obstructive pulmonary disease

EPOA: Enduring Power of Attorney

GTO: Getting to Outcomes

HrQoL: Health related quality of life

KTA: Knowledge to Action

OCH: Otago Community Hospice

PaCKS: Palliative Care Knowledge Scale

QD: Qualitative description

SES: Socioeconomic status

SSI: Semi-structured interviews

WHO: World Health Organisation

Chapter 1

Introduction

Patients engaging in palliative care due to life-limiting illnesses may experience a range of debilitating symptoms throughout their treatment period (Cipolat Mis et al., 2015; Du et al., 2015; Stephenson et al., 2021; Vij et al., 2013). These symptoms can negatively affect many aspects of patients' lives, including sleep, relationships, pain levels, and mental health, all of which can lead to patients experiencing a lowered quality of life (Du et al., 2015; Stephenson et al., 2021). For the purposes of this thesis, the definitions of palliative care and hospice care that I will be working from are the following. Palliative care is defined as care that focuses on improving patients' quality of life when they are experiencing life-limiting illnesses (Hui et al., 2013). Hospice care is defined as care that is designed to support patients and their families when living with a terminal illness, and it is included under the umbrella of palliative care (Hui et al., 2013).

With these symptoms and negative outcomes for palliative care patients in mind, this thesis aims to demonstrate one potential way to improve these outcomes. This will be completed by proposing key features and elements of a patient-focused education programme, which can then be developed at a local Hospice service.

This research was conducted primarily at the Otago Community Hospice (OCH), which is located in Dunedin/Ōtepoti in the South Island of New Zealand. The OCH was formed 30 years ago, and currently supports patients and their families within the Otago region (Otago Community Hospice, 2023). The guiding vision for OCH is stated as "supporting people with terminal illness to live and die well" (Otago Community Hospice, 2022). In practice, OCH provides free support for patients and their families, whether this be in their own homes, in rest-home care, or with the Dunedin-based in-patient unit (Otago Community Hospice, 2022). Most work directly with patients is undertaken in their own homes by Care Coordinators who manage patient health and symptoms within the community.

During 2022 OCH supported 750 patients, with a relatively even split of gender – 55% male and 45% female (Otago Community Hospice, 2022). Patients were mostly over the age of 55 years old, with only 7% of patients being under 55, and the largest percentage of patients at 33%, being 75-84 (Otago Community Hospice, 2022). Of patients that access OCH services 75% have cancer (Otago Community Hospice, 2022), a statistic that guides the research component of this thesis. Most studies discussed during the literature review portion of this thesis will focus on patients with cancer to best reflect the realities of most OCH patients and their needs.

OCH provides an education programme that is available to family/whānau members and carers of those patients experiencing life-limiting illnesses, called the Kōwhai programme. In 2022, 146 carers attended this programme, to learn more about how to best support their loved ones (Otago Community Hospice, 2022). Topics include nutrition, medication management, grief and loss, fatigue, self-care, and end-of-life/advanced care planning (Otago Community Hospice, 2023). Conversations have arisen in recent years from both staff and patients about the need for a similar programme, tailored specifically for patients and their needs.

In 2021, I completed an internship at the OCH as part of my studies towards my Masters of Health Psychology. As part of this internship, I completed some preliminary research into what a patient-centred programme could look like at the OCH. This thesis is a natural continuation of this research, expanding the scope and direction. My intention is to produce a proposal and make recommendations that the OCH can draw from to create such a programme for patients. I worked closely with an on-site supervisor, Denise van Aalst, both in my internship and during this thesis. Denise is the Coordinator of the Kōwhai programme, and has a strong desire to see a parallel patient-centred programme be created.

As well as completing my internship at the OCH, I have also volunteered for their biography service since early 2021. In providing this service, volunteers interview patients about their lives, and then create a biography for them and their family to keep. During the course of this thesis, I was on a break from the biography service, and none of the patient participants for this research had been previously interviewed as part of the biography service. This was to minimise any potential conflict of interest. My experience with the biography service has enabled me to feel comfortable talking about death and dying with patients, and I am aware of some of the physical and emotional needs that patients might have. These needs will be discussed further within the methodology chapter.

1.1 Thesis outline

The thesis is divided into five chapters. The first chapter is this brief introduction positioning the research and the research context, as well as OCH. The second chapter is a literature review, detailing evidence based practice in palliative care education research and exploring Implementation Science as a scientific approach, followed by the situating of the current research and its aims. The third chapter details the methodology on which this research is based, and describes the methods used during the research process itself. Chapter four presents the findings of the research, alongside some initial analysis. Chapter five is a discussion which deepens the preliminary analysis undertaken in the Findings chapter. There will also be recommendations about the development of a patient-centred programme at the OCH, avenues for future research, discussion on the limitations of this thesis, and concluding remarks.

Chapter 2

A Review of the Literature

2.1 Introduction to palliative care and palliative care education

Palliative care is care that is designed to elevate quality of life for patients with life-limiting illnesses (Mojali et al., 2020; WHO, 2023; Yoon et al., 2006). Palliative care can include minimising pain for patients, providing spiritual care, and empowering patients to die at home where possible (Shahid et al., 2018). Qualitative studies in the palliative care space have found that patients want to focus on pain management, how to avoid necessarily prolonging the process of dying, having a sense of control about what they are going through, and finding closure, whatever that means for them (Back, 2008). Patients emphasise the need to talk about these issues in a space with health professionals, as well as with other patients so as to access non-judgemental and useful support (Back, 2008). In the New Zealand context, the Ministry of Health projects that the need for palliative care will increase by 51% between 2016 and 2038, showing the importance of efforts that have been made in recent years to increase the likelihood that patients can access this care when they need to (Ministry of Health, 2016).

There has been much written about the importance of social support and education programmes for cancer patients and those with other life-limiting illnesses in combating some of the negative outcomes to patients outlined in the previous chapter (Du et al., 2015; Papadakos et al., 2021; Prevost et al., 2019; Stephenson et al, 2021). Providing education to patients has been shown to “help reduce anxiety and depression, better prepare patients for their treatment, and improves overall quality of life” (Papadakos et al., 2021, pp. 1398).

Although the literature referred to in the previous paragraph is not specific to palliative care across the spectrum, the similarities between care for cancer patients before they reach the palliative care stage, and care for those patients with other life-limiting illnesses mean that the findings and conclusions may be considered and applied in relation to palliative care patients. Similarities in experiences can include exposure to highly medicalised environments which patients may not previously have been involved with, disruption in regular life including changes in mobility, appetite and appearance, pain management, and the impending or possible sense of death (Cipolat Mis et al., 2015; Du et al., 2015; Stephenson et al., 2021). More specifically, of the whole intake of OCH patients in 2022, 75% were cancer patients (Otago Community Hospice, 2022). This further suggests that the literature in relation to social support and education programmes for cancer patients is relevant to palliative care and specifically this thesis.

Vij et al. (2013) report that upwards of 46% of a sample of prostate cancer patients relied on psychosocial support as their main coping mechanism during their treatment period. Papadakos et al. (2021) argue that “patient education has been shown to help reduce anxiety and depression, better prepare patients for their treatment, and improve overall quality of life.” Stephenson et al. (2021) found that cancer support programmes helped patients to reduce their stress levels, increase their energy, have better quality of sleep and increased how empowered they felt.

Brooker et al. (2020) argue that particularly for cancer patients, group-based education programmes can help to address issues of social isolation that are frequently experienced in these patients. Group education sessions are shown to be particularly effective when working with cancer patients, as participants feel able to share experiences, tips, and have conversations with others who are going through similar experiences (Prevost et al., 2019).

However, best practice approaches to development of education material is not always followed, leading to inconsistent evidence about effective methods to educate patients in ways that lead to positive outcomes (Du et al., 2015). Cipolat Mis et al. (2015) argue that it is integral for patients to be included in the development of any programme to improve the effectiveness of its delivery. Patient involvement in the programme development process ensures that their viewpoints are heard, and means that relevant patient-focused information can be delivered in these education programmes. Cipolat Mis et al. (2015) also argue that patient empowerment such as having control over healthcare decisions is vital within these programmes, and should be considered when such programmes are being created. However, Roberts (2021), complicate this view of patient empowerment, adding that there can be tensions created by false forms of empowerment towards patients, and that this can in fact be associated with negative outcomes. In this context, false forms of empowerment might include asking for patient perspectives, but not actioning these in ways that have benefit to patients within an education programme. The authors argue that ‘agency’ is a more effective way to position patients and the power they have to change their situation (Roberts, 2021). Patients may have agency over some aspects of their care, and the more agency that they feel they have, the more they are likely to thrive (Roberts, 2021). This positioning of patient agency and viewpoints leads us to a critical evaluation of previous palliative care education interventions.

2.2 The New Zealand context

In 2001, New Zealand introduced the New Zealand Palliative Care Strategy to provide funding and support to the creation of palliative care services (Macleod et al., 2012; Muircroft et al., 2010). The vision of this strategy is as follows: “All people who are dying and their family/whanau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a coordinated way” (Macleod et al., 2012, p. 51).

In 2012, Macleod et al. conducted a study to evaluate how much knowledge New Zealanders had about palliative care and Hospice services more generally. Participants were recruited through an online survey, and 1011 participants responded. Participants were asked to rate on a Likert scale, their knowledge about various components of palliative care. Of the respondents, the gender split was mostly even, with the age range being from 18-70+. Many misconceptions about Hospice care were held by participants; half of participants believed that hospices services are where patients go when they are ready to die, many believed that Hospice services are only offered to patients and not their families, and many participants believed that Hospice predominantly cared for patients physical needs, rather than emotional or psychological needs (Macleod et al., 2012). Participants older than 50 were more likely to know about the broad range of services Hospices provide, while those under 30 were the least likely to be aware of the services provided (Macleod et al., 2012). This study showed that New Zealanders hold a range of incorrect views about palliative care and Hospice level care that could stand to be challenged through an educative approach.

Within the Palliative Care Strategy, Māori were considered as a group that needed policies and procedures to support them within palliative care, particularly because Māori and non-Māori practices surrounding death are significantly different (Muircroft et al., 2010). On top of the different cultural norms surrounding death and dying, Māori are significantly more likely to die from life limiting illnesses, and to be diagnosed at later stages of illness progression (Muircroft et al., 2010). With these considerations in mind, it is important that health interventions in the palliative care space in Aotearoa address Māori needs within the intervention.

A study conducted by Bellamy and Gott (2012) aimed to look at the palliative care priorities of a diverse range of participants within New Zealand. The authors interviewed eighty participants who worked in Hospice or palliative care workplaces, and asked them their views about palliative care provisions for Māori, Pacific Island, and Asian populations in Aotearoa (Bellamy & Gott, 2012). 55% of those interviewed were NZ European, 4% were Māori, 1% were Pacific Island, and 10% were Asian (Bellamy & Gott, 2012).

The findings of this study illuminated some key points about culturally responsive Hospice care within Aotearoa. The findings illustrated that having family close during the final stages of life was seen as important in Māori and Pacific Island culture, and that family members being active agents in the care of sick family members was integral (Bellamy & Gott, 2012). Another point raised was that Hospice services are not always equipped to deal with high numbers of family members, and Māori, Pacific Island, and Asian patients may feel excluded from the services as a result, because they perceive their family as not being welcome in the healthcare space (Bellamy & Gott, 2012).

This study raises important points, but has a key limitation of only interviewing service providers, rather than patients themselves. The service providers were also predominantly NZ European, so there is a limit in how far we can extrapolate these findings. However, this study goes some way in situating some of the needs of culturally diverse patients, as we move to the next section of this literature review.

2.3 Critical review of previous palliative care education interventions

In recent years, the WHO has developed a focus on patient engagement, to empower patients, family members and carers to centre patients within their own care (WHO, 2016). Research in recent years has attempted to understand the patient experience of illness, and incorporate this into educative interventions that are aimed towards those undergoing palliative care treatment. What follows is an analysis of various patient-centred programmes designed for those with life-limiting illnesses who are engaging in palliative care.

A study conducted by Perry et al. (2021) evaluated an intervention that increased readiness of patients to engage in palliative care treatment. They found that upwards of 70% of adults do not know what palliative care is, much less what treatment looks like (Perry et al., 2021). There are misconceptions about palliative care that mean that patients see palliative care treatment as meaning they are close to death or surrendering in their journey with their illness (Perry et al., 2021).

Perry et al. (2021) developed an intervention that worked in conjunction with palliative care services in New Orleans, USA. The authors took an approach that allowed them to work closely with a variety of research stakeholders, including staff at palliative care services, patients accessing the services, and family members of the patients (Perry et al., 2021). Patients recruited for this study had metastatic cancer, were over 18 years old, and must not have had a prior palliative care stay at the centre the researchers worked at. All stakeholders made recommendations about what the intervention should involve, and gave feedback on early drafts produced by the researchers (Perry et al., 2021).

The researchers created two versions of a video-based intervention, one that was more advanced in how the health-related information was communicated (12 minutes long), and a shorter version, aimed at those who had poorer health literacy (7 minutes long) (Perry et al., 2021). Findings showed that knowledge about palliative care improved by 83.1% across participants, from pre to post-vention surveys. Attitudes towards palliative care changed within participants as well, with participants reporting a significantly lessened fear of palliative care, a higher level of trust in the benefits of palliative care, and increased intentions to use palliative care services in the future (Perry et al., 2021).

What these results suggest is that a well thought-out approach to developing interventions for patients is key in ensuring that they have positive health outcomes for patients. The videos were created using a mix of theory and psychology principles to increase the accessibility of theory for patients. This theory was then combined with collaboration with a variety of stakeholders, to ensure that the intervention actually met the needs of the patients it was purporting to help (Perry, et al., 2021). Stakeholder engagement can add barriers, such as increasing research cost and time, as well as feedback processes from stakeholders. However, this study demonstrates that taking time to weave stakeholder opinions with theoretical frameworks can produce interventions that have significant effects on patients and their view points. The results reported in this study were three to five times stronger than what is classified as a large effect, which shows the strength of this two-pronged approach (Perry et al., 2021).

Oldenmenger et al. (2018) conducted a literature review of how effective patient-based education interventions have been in relation to improving cancer-related pain. Although this is not a strictly palliative care focused study, pain management is a hugely important aspect of palliative care for patients and practitioners, which is why it is included in this literature review and the later discussion. Of patients with cancer-related pain, 38% of these rate their pain as moderate or higher (van den Beuken-van Everdingen et al., 2016).). There are a range of barriers to addressing cancer-related pain, with patients reporting a lack of knowledge about pain medications and how they work, as well as non-adherence to the specifics of how the medications are supposed to be used as two significant barriers (Oldenmenger et al., 2009; Yates et al., 2002)).

The authors conducted a literature review to identify studies that met with the criteria for their study. This process led to 26 studies being suitable. These studies were randomized control trials, focused on interventions created for patients experiencing pain related to their cancer, and included patients receiving some sort of education about the pain they were experiencing (Oldenmenger et al., 2018). Four thousand, seven hundred and thirty five patients were included within these articles, in which studies had been conducted in the USA, Europe, Asia, Australia and Canada (Oldenmenger et al., 2018). The interventions included in this study were behaviour change focused, related to the management of patient pain, and were delivered by a healthcare professional (Oldenmenger et al., 2018). Eighty five percent of the studies involved face to face sessions, and most had repeated contact with their patients. Thirty one percent of the studies found that the patients involved in the interventions did experience an improvement of the intensity of their symptoms following the intervention (Oldenmenger et al., 2018). Medication adherence amongst patients increased in six of the studies analysed in this review, showing that there is an evidence base to draw from when aiming to increase medication adherence in patients.. One significant issue that the authors uncovered is that there was no standardized approach across the studies to measure pain outcomes. Pain intensity was measured as an average, or on a scale, and with varying timeframes, ranging from the last day, to evaluating patient pain over the past two weeks (Oldenmenger et al., 2018). This meant that despite the success of some of the studies, because the baseline measure varied so much, no specific recommendations could be made for future intervention development as there was not a consistent measure to draw from (Oldenmenger et al., 2018). This limits any positive effects that the outcomes of these articles may have. This literature review shows the importance of evidence-based practice being shared domestically and internationally, so that outcomes can be measured in a way that will best be able to serve patients in the real world. If studies cannot be compared and applied in a standardised way for patient health outcomes, the real world applications are limited. By evaluating interventions that measure patient outcomes in the same way, then researchers can evaluate the approaches that have the most positive impact on patients and these can be utilised in real world settings more effectively.

A 2000 article by Steinhauser et al., attempted to rank the factors that were considered most important to palliative care patients who were approaching end of life. This study recruited 1452 participants, who were broken up mostly evenly between patients, family members, physicians and other care providers (Steinhauser et al., 2000) The patients in the study were experiencing a variety of illnesses such as cancer, lung disease, and renal disease, and the diseases had progressed to end-of-life care. Patients and physicians often rated things very differently – i.e., what patients saw as important, was not rated as important to physicians (Steinhauser et al., 2000). This difference in opinion shows why it is important to have patient voices present when conducting studies like this. Without patients being able to share their opinions and viewpoints, interventions may focus on areas that do not benefit them in significant ways.

Patients specifically rated the following items as being very important to them at end-of-life: having mental awareness of what is happening around and to them, having their funeral planned in advance, not feeling burdensome to their family, and spirituality (Steinhauser et al., 2000). All groups rated pain management as important, as well as having a positive relationship between patients and healthcare providers (Steinhauser et al., 2000). Patients did not rate the ability to discuss their fears as particularly important at end-of-life (Steinhauser, 2000). What this might indicate is that once patients are requiring end-of-life care, they have moved beyond the need to discuss their fears. Education-based interventions for earlier stage palliative care patients may or may not choose to focus on discussing fears with patients – perhaps at an earlier stage these discussions might be seen as more important.

Atena et al. (2022), conducted a study evaluating the level of knowledge patients had about palliative care. The participants that the authors studied answered a three part questionnaire, a demographics section, a question about where they get their information about palliative care, and they completed the Palliative Care Knowledge Scale (PaCKS) (Atena et al., 2022). One hundred and three questionnaires were completed, with participants' mean age being 36.2, the majority being Iranian nationals, 63.1% male, and 58.3% had at least high school level education. Participants outlined their sources of palliative care knowledge as follows: 38.8% reported accessing information via media (television and movies), 36.9% from their treatment team, 28.2% received information from their relatives or friends, 25.2% from online searches, and 19.4% found their information via books or educational pamphlets (Atena et al., 2022). Only 29.1% of participants had a good level of knowledge about palliative care, 50.5% had a moderate knowledge level, and 20.4% had a weak level of knowledge about palliative care (Atena et al., 2022).

Although this study is based in Iran, and there may be significant cultural and social differences with New Zealand based patients, this study echoes previous international studies regarding patient knowledge about palliative care. Atena et al. (2022) note that, "81.3% of oncology patients in London, 63.1% of cancer patients in Japan, 61.1% of advanced cancer patients in the United States, 60.7% of patients with cancer in Ethiopia and 54% of patients with advanced cancer in Singapore do not know enough about palliative care or hospice care". Recent studies based in New Zealand regarding patient knowledge of palliative care are limited, and Atena et al.'s (2022) study was chosen as a recent example of the limits of patient knowledge about palliative care.

Knowledge about palliative care is important for a variety of reasons. Patients who engage in palliative care early in their diagnosis experience “improved physical symptoms, increase in quality of life, survival time, tendency for death to occur at home, and satisfaction with care, and reduction in depression, emergency visits, and hospital admissions” (Atena et al., 2022). The authors note that patients who engage in palliative care later or not at all, receive more invasive treatment options and have a higher risk of death. One of the biggest inhibitors to patients accessing palliative care is a lack of knowledge about what this kind of care involves and how it would help them in their journey (Atena et al., 2022; Perry et al., 2021). Another barrier for patients is the belief that that those admitted to palliative care treatment are nearing the end of their life (Atena et al., 2022).

The Atena et al. (2022) study shows that advances on patients’ knowledge about palliative care urgently needs to be made. A consistent myth is that palliative care is for those at the end of life, which is not always the aim of palliative care. How patients found their information about palliative care was also of concern. Books and educational pamphlets were rated as the least utilised resource, and education programmes did not feature at all as a way that patients found out about palliative care. As Atena et al. (2022) noted, accessing palliative care early makes for better outcomes for patients, so this could be imperative to the development of education programmes within this space. Education programmes could allow healthcare providers an alternate forum to address knowledge gaps that patients have about palliative care treatment.

A study conducted by Chan et al. (2022) focused on patients with chronic kidney disease and looked at the effectiveness of a Brief Hope Intervention (BHI) for patients. Hope as an intervention has been used in previous studies and has been found to have many positive effects on patients. These positive effects include increased cognitive flexibility and creativity, heightened engagement in care decisions, increased desire to meet their goals, and a decrease in physical and psychological symptoms in patients (Chan et al., 2022).

This study was a single-blind, two arm, randomized control trial. Participants were over 18, alert, literate in Chinese, and experiencing end stage kidney disease. There were 36 participants in each group, and baseline and end point surveys were conducted by a research assistant who was not involved directly with the practical elements of the study (Chan et al., 2022). Both groups of participants received a one hour education session facilitated by nurses. The content of this programme included goal setting, problem-solving techniques and how to increase positive self-talk. Patients had access to a follow up out-patient clinic where their illness and symptoms were monitored. The control group received check in phone calls after their treatment for two weeks, and the intervention group received a four week BHI facilitated by healthcare providers. The sessions were broken into three main areas; goal setting, problem-solving and positive self-talk (Chan et al., 2022).

Results of the Chan et al (2022) study showed that quality of life greatly improved within the intervention group following the conclusion of the study. The intervention group also experienced less conflict in their decision making processes (Chan et al., 2022). Finally, motivation was strengthened in the palliative care study participants, to the point where they felt more able to implement behaviour change that led to better health outcomes (Chan et al., 2022). This study shows that even brief interventions can have a statistically significant influence on patient wellbeing, particularly when education is targeted towards specific outcomes – i.e., in this study, goal setting and problem solving. However, despite producing a significant result, this study has limitations. The data was collected immediately after, then one month following the intervention. This is a brief time period, and does not show if there was a real difference in longer-term behaviour and outcomes for the patients. It would be useful to know if the heightened motivation patients felt in the intervention group translated to longer term change in their behaviour regarding their illness, and future studies could consider this more practical application.

Another behaviour change study, conducted by Smalley et al. (2022) in the United Kingdom, looked at patients' ability to self-manage their illness. The illness in question in this study was bronchiectasis. Understanding how to manage their illness gives patients a significant boost in confidence, which makes them more likely to feel empowered to self-manage some other aspects of their illness (Smalley, et al., 2022). Self-management of an illness can involve exercise, monitoring own symptoms, and having confidence to ask questions during meetings with healthcare providers (Smalley et al., 2022). Identifying the gaps in knowledge means that practitioners can begin to address these gaps and introduce targeted education approaches for patients. Behaviour change interventions for patients experiencing life-limiting illnesses are becoming increasingly commonplace (Smalley et al., 2022), but there are a range of opinions on how to best to create education approaches that help patients do this, and even which knowledge gaps to address (Smalley et al., 2022). If those gaps in knowledge are able to be identified as in Chan et al. (2022), then it means education targeted towards patients can become more specific and useful for patients (Smalley et al., 2022).

Lee et al. (2022), conducted a study that looked at health related quality of life (HrQoL) in patients with advanced cancer. The authors surveyed 600 patients in Singapore with stage 4 cancer, and conducted surveys with these patients every three months until their death. Fifty nine percent of patients died during the study period, which lasted for one year. Results from this study found that 47% of the patients that were surveyed had a high HrQoL journey during the final year of their life, 32% experienced progressively decreasing HrQoL during their final year of life in which physical and emotional wellbeing declined but social quality of life stayed high, 13% experienced an asymmetric HrQoL decline in which physical and emotional levels were high but social quality of life was low, and 8% experienced overall low HrQoL (Lee et al., 2022). The authors noted that this contradicts other studies, which have shown that there is usually a precipitous HrQoL decline in patients during the last period of their life (Lee et al., 2022).

The exception to this was patients with a low socioeconomic status (SES), who did experience a greater decline in HrQoL (Lee et al., 2022). Those patients with the greatest decline in HrQoL experienced the longest hospital stays during the final year of life, which affirms many patients' desire to stay at home during end of life care (Lee et al., 2022; add more references to this statement). This study shows that future education interventions must have a component that aims to improve HrQoL within attendees, for a variety of reasons. Attention needs to be paid to patients coming from a lower SES background, to ensure that they are receiving equitable healthcare information within education programmes, to prevent the steep HrQoL decline that was outlined in Lee et al.'s (2022) study. However, when we consider that those with low SES were the most likely to experience a greater decline in HrQoL, this picture is complicated. For example, education sessions do not address the ability for lower SES patients to pay their bills or complete physically demanding household tasks. In this respect, education sessions could have components that provide information about how to access services that could support these needs. This will be discussed further in the discussion chapter of this thesis.

A Mexican study by Villarreal-Garza et al. (2020) looked at the experience of young breast cancer patients who undertook a supportive care programme related to their illness. The programme is the first of its kind in Mexico to address information sharing in regard to health (Villarreal-Garza et al., 2020). The programme had been delivered to 599 patients at the time of article publication. To be eligible for the programme, patients must be under 40 years of age and recently diagnosed with breast cancer (Villarreal-Garza et al., 2020). On top of the delivery of the education programme, participants were given referral support by their educator, had access to a patient-centred WhatsApp group, had access to a psychology support service and had access to monthly facilitated sessions with their family about breast cancer healthcare and coping with the illness (Villarreal-Garza et al., 2020).

In this evaluative study, the programme was rated as useful or very useful by 97% of patient participants. The main areas that patients singled out as being particularly useful was the programme helping them with psychological support in relation to their illness, as well as providing them with practical knowledge about breast cancer (Villarreal-Garza et al., 2020). The external support services outside of the educational format were used by the majority of participants, indicating that there is appetite within patients for continued support, even if this is on a peer level rather than professional (Villarreal-Garza et al., 2020). Most patients rated the programme as useful or very useful in relation to improving their ability to cope with their diagnosis (Villarreal-Garza et al., 2020). A small but significant minority, 13%, of participants found the educational content distressing for the following reasons; a fear of having to commence invasive treatment, feelings of uncertainty about their future, fear about fertility issues, and feeling overwhelmed at the amount of content presented to them (Villarreal-Garza et al., 2020). This bears mentioning when considering the development of a local education programme, as practitioners can learn from the areas that have upset participants previously and take steps to minimise and mitigate the risk of upset for patients by adapting the programme in a way that addresses these concerns.

This literature review has aimed to situate palliative care education research as it currently stands, by beginning at a New Zealand perspective, moving to other Western countries' approaches, then broadening into recent interventions on a global scale. What was uncovered in this literature review is that stigma appears to play a large part in preventing patients from seeking palliative healthcare at stages where it would be most beneficial to them. Patients in Aotearoa also face challenges in accessing culturally responsive Hospice care, and this extends to education about their illness and how to manage this. Of the interventions evaluated in this literature review, the studies that took practical, symptom management, and positive empowerment based approaches to palliative care education seemed to have the strongest outcomes for patient wellness. Further work needs to be undertaken to standardise approaches to evaluating patient outcomes from education programmes, so as to ensure that interventions can be compared and contrasted effectively.

2.4 Introduction to Implementation Science

When developing education interventions for use in the healthcare field, it is assumed that researchers and facilitators will use research and practices that are embedded in a strong evidence base, so as to ensure the best outcomes for participants. However, in practice, even with the best of intentions and prior knowledge of evidence-based practice, the reality of implementing such interventions in ways that will be effective is elusive for practitioners (Albers, Shlonsky & Mildon, 2020).One possible approach to bridge the gap from good intentions to concrete outcomes is Implementation Science.

2.5 A review of the Implementation Science literature

Implementation Science is a relatively recent methodology that was created to effectively implement science into professional practice, and to improve the quality and effectiveness of these initiatives (Eccles & Mittman, 2006; Nilsen, 2015). After initially being used within the health care space, Implementation Science has grown in scope to cover many disciplines and areas of research (Albers, Metz & Burke, 2020; Nilsen, 2015; Westerlund, Nilsen & Sundberg, 2019). There are three main areas that Implementation Science aims to address through use of various frameworks and models. Firstly, there is facilitating the process of research becoming practice. Secondly, Implementation Science approaches aim to gain an understanding of the factors that influence the outcome of any given implementation. Thirdly, there is a focus on evaluating the success of the implementation. For the purposes of this research project, points one and two will be explored in greater depth than point three, as evaluating the effectiveness of an implementation is beyond the scope of this thesis.

There are a variety of reasons why it is important to come from an Implementation Science approach when establishing interventions. As Nilsen (2015) writes, if researchers do not have a strong theoretical basis to base the creation and delivery of their intervention from, then it is nearly impossible to know why certain aspects of the intervention succeed or fail. Without this knowledge, we cannot isolate factors that positively affect any given intervention, nor can we use strategies that increase the likelihood of success (Nilsen, 2015).

However, even with the knowledge that a strong theoretical basis increases researchers' knowledge about an intervention, there is still a significant gap between the existence of supporting evidence for an intervention, and the likelihood that this evidence is actually used (Albers, Shlonsky & Mildon, 2020). This is referred to as the research to practice gap (Albers, Shlonsky & Mildon, 2020; Fernandez et al, 2019; Westerlund, Nilsen & Sundberg, 2019; White, 2018). In practice, what this means is that even if a practitioner wants to integrate the latest best practice research into their intervention, they may not be able to. Even if the research they need exists in the first place, there is still a substantial barrier in how long research takes to be applied in practice; on average the gap between research and utilisation is 17 years (Albers, Shlonsky & Mildon, 2020; Fall et al., 2019). This problem is another reason why Implementation Science is seen by researchers as a beneficial approach to bridging the delay from research to practice. Participants can only stand to benefit from an intervention if they actually receive it, and because Implementation Science is a method practitioners can use to enhance effective development of their interventions, this may reduce the time it takes for research to be applied in real world interventions (Albers, Shlonsky & Mildon, 2020).

There is also the question of fidelity within implementation of interventions (Fernandez et al., 2019). This can occur in two areas. Firstly is with practitioners themselves. There has been evidence to suggest that practitioners are not always aware of how to effectively implement best practice, which means that the interventions that are used are not effective (Westerlund, Nilsen & Sundberg, 2019). Secondly, the participants in the interventions themselves affect the fidelity of the implementation in a variety of ways. This can happen through low adoption rates of the intervention (Westerlund, Nilsen & Sundberg, 2019), not using the intervention as intended, or altering the intervention without input from practitioners (Fernandez et al., 2019). This means that the best-practice approaches are watered down, or inadvertently removed, reducing the effectiveness of the implementation of a particular intervention.

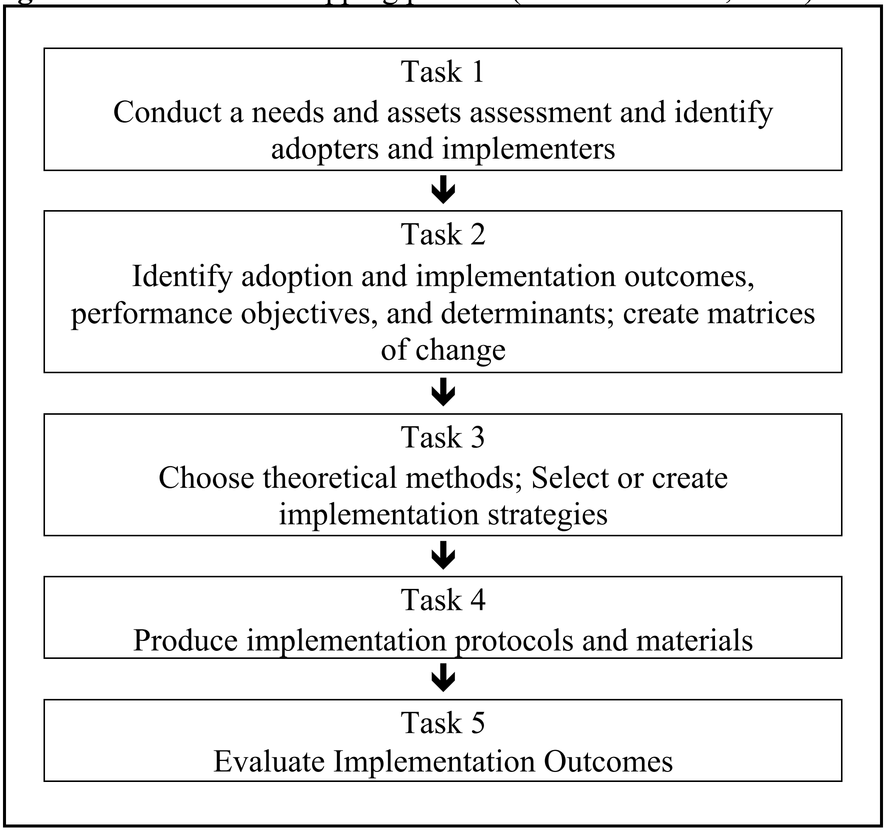
2.6 Implementation Science models

This is the basis of why Implementation Science is important and useful as a theoretical framework. I will now cover some of the different models or processes within Implementation Science, and how these are used in context.

Firstly, Implementation Science uses a variety of key concepts that will be used at different points throughout this chapter. These include the following:

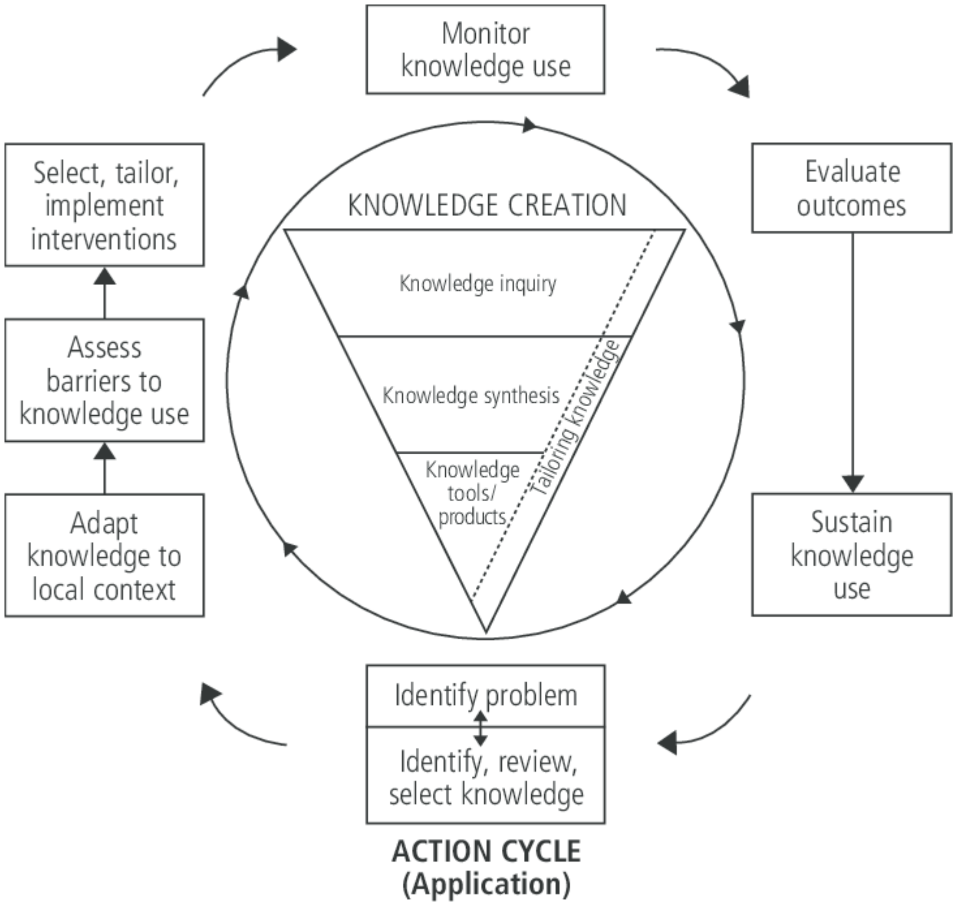
- Process models: These models outline the stages involved in actually implementing an intervention. There are process models that guide the design of interventions, and other models that guide the spread and scale of implementation.
- Theories: Theories describe methods of change on individual, organisational, system, and community levels.
- Frameworks: These can help explain the various factors that affect outcomes when implementing an intervention.
- Approaches: These are tools and strategies that are used throughout an implementation process.

Figure 1: Intervention mapping process (Fernandez et al., 2019).



There are two main process models used within Implementation Science that can be used when designing an intervention. The first is intervention mapping, as shown in Figure 1. This is a process model that helps guide the design of health promotion interventions in particular. As demonstrated in Figure 1, there are five steps to intervention mapping (Fernandez et al, 2019). Firstly, practitioners conduct a needs assessment to decide what needs to change in the context, and who will be the recipients of the intervention. Next, the practitioners choose the desired programme outcomes, as well as how change will be enacted within participants. Thirdly, the practitioners select evidence-based theories as methods that align with the changes the practitioner is wanting to enact in participants. The practitioner then must create the intervention or programme, with the structure being refined to ensure maximum fidelity. A plan to implement the programme is then developed, with potential programme users identified. Practitioners then consider the sustainability of the intervention and consult with stakeholders about longevity and how the needs of participants will be met by the programme long-term. Finally, an evaluation plan is created so that the effectiveness of the programme can be established (Fernandez et al, 2019). A key feature of implementation mapping has been to ensure that the fidelity and sustainability of any given programme is maintained (Fernandez et al, 2019).

Figure 2: Knowledge to action process (Graham et al., 2006).



The other main process model is Knowledge to Action (KTA) (see Figure 2), which is used more frequently in healthcare, rather than public health. There is less specific structure to KTA, and there is scope to draw on various theories and models to support its use (Graham et al., 2006). The main steps of KTA are identifying a problem, adapting best-practice knowledge to the specific context the researcher is working in, assessing barriers and facilitators to knowledge, selecting appropriate interventions, and evaluating outcomes (Graham et al., 2006). KTA is fluid in its approach, and there is an emphasis on going in and out of different stages at various times during the research process, meaning outcomes are not pre-determined (Graham et al., 2006).

On top of the models used for designing interventions, there are also a variety of process models used for implementation, spread and scale. Implementation can be defined as working within systems and understanding where our system is contained to, and where it connects to other systems (Moore & Khan, 2021). Spread can be defined as a horizontal type of diffusion of an intervention, to spread best practice knowledge in as many areas as possible within the system we are working within (Ilott et al., 2013). Scale is defined as vertical diffusion, a top down approach to ensure that an intervention has longevity within the system being worked within (Ilott et al., 2013). The first model is Getting to Outcomes (GTO), which is the only implementation process model that has been scientifically tested in a randomised control trial (Chinman et al., 2017). It is an approach that is used frequently in community interventions (Chinman et al, 2017). GTO has ten steps, which include conducting a needs assessment, identifying goals, isolating best practice approaches, ensuring fit with a host agency, ensuring capacity to facilitate the programme, planning activities, providing a guideline for completing process and outcome evaluations, supporting researchers to improve the programme, and offering guidance on how to sustain a programme if it is effective for the target population (Chinman et al, 2017).

Another model is Active Implementation, an approach often used within social education programmes. This model requires facilitators to undergo training to be used effectively, and has four main steps, which are moved through fluidly. These steps are exploration – assessing needs and fit; installation – find resources and support for the implementation; initial implementation – implement an intervention and improve it as new data is formed about it; and full implementation – a consistent approach based on positive outcomes from previous steps (Moore & Khan, 2021).

The next model is the Quality Implementation Framework (QIF), which attempts to draw together many Implementation Science frameworks into one cohesive model (Albers, Shlonsky & Mildon, 2020). The main tenets of this model are as follows (Albers, Shlonsky & Mildon, 2020). Implementation happens in a variety of stages and a needs assessment is completed by practitioners before an intervention is developed. The ‘readiness’ of both potential participants and host organisations is considered deeply by practitioners, and this guides how they develop an intervention (Albers, Shlonsky & Mildon, 2020). QIF emphasises building the skills of host organisations so that the intervention can have longevity outside of the practitioners who develop it, and the model emphasises frequent evaluation and feedback mechanisms to ensure fidelity (Albers, Shlonsky & Mildon, 2020).

There are also frameworks that can be used to evaluate whether a context or organisation is ready for an intervention to be implemented. One such framework is the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al, 2009). The CFIR is a framework that encapsulates many aspects of an implementation approach. The first area of interest within CFIR is the context or organisation that an intervention is being implemented within. Damschroder et al (2009) write that interventions must be malleable to their specific context and changeable, while still fitting into best-practice methodology. The inner and outer settings are also key concepts to CFIR. The outer setting is the context in which the host organisation exists within – i.e., the social and political context (Damschroder et al., 2009). The inner setting refers more to the organisation itself, and the dynamics that are at play in which the intervention will be launched into (Damschroder et al., 2009).

Another area of interest in CFIR is the individuals that are involved with an intervention – both those implementing it and receiving it. This dynamic relates back to the discussion on fidelity, as individuals within CFIR are seen as agents who have their own mindsets and viewpoints (Damschroder et al., 2009). In this sense, individuals may adapt an intervention, often in conjunction with other practitioners or service users. In context, what this means is that as practitioners, we need to be aware of the individuals we are working with within an intervention, to ensure that their views and goals are being met within the fidelity of the implementation process. The final area of CFIR focusses on the implementation process itself. This involves working with individuals from different parts of the organisation to implement the intervention effectively.

The models discussed offer a variety of ways of undertaking Implementation Science focused research. Intervention mapping (Fernandez et al., 2019) provides a straightforward way of understanding how to structure an Implementation Science approach, and is particularly useful for health promotion focused research. Its simple structure contrasts the approach with the Knowledge to Action approach, which is more fluid and has less of a set structure (Graham et al., 2006). This means that those newer to the Implementation Science field might find intervention mapping a more intuitive approach, with a clear end goal. KTA can be cyclical (Graham et al., 2006), and it could be hard for researchers to know when to finish the process of implementing an intervention.

Getting to Outcomes (Chinman et al., 2017) is an approach that fits well with intervention mapping, as the process it follows is very similar, while focusing on the spread of the intervention. As an approach that has been evaluated in a RCT, it is an appealing choice for those wanting to implement best practice approaches in a way that is likely to have a lasting effect (Chinman et al., 2017). Active implementation may not be favoured by researchers, as training has to be undertaken to be used effectively (Moore and Khan, 2021). An approach that requires facilitators to undergo training might be an inhibitor to uptake, and might have effects on the fidelity of future interventions.

The models and frameworks used for this thesis will be explored next.

2.6 Linking palliative care education with Implementation Science

As shown in the previous section, Implementation Science provides a strong foundation for the development of a patient-focused palliative care education programme. As Effendy et al. (2022) note, research findings have limited relevance unless they are put into practice to support patients effectively. I will now discuss how palliative care education research can be linked with Implementation Science to produce outcomes that benefit patients.

As Roberts (2021) described, it is important for patients to feel a sense of agency over their care and health outcomes. This is why I felt it was key to gain patient voices within this study, so as to improve patients' sense of agency and ensure their needs are met within a research context.

Patient-focused research has developed in recent years to support patient participation in the formation of health promotion interventions (Yoon et al., 2006). Patient-centred education has developed from informal approaches to facilitated programme delivery to increasingly systematic and "carefully implemented" ways of approaching education about palliative care (Yoon et al., 2006, p. 131). This shows the growing importance of Implementation Science within the palliative care education space, and why it is an approach that is complementary within palliative care. A range of methods can be used for such systematic, implementation-based approaches, including counselling, encouragement, advice, behaviour change approaches and how to maintain these, and symptom management more broadly (Yoon et al., 2006).

A study by Moore et al. (2020) conducted a review of articles that had undertaken palliative care education intervention, to evaluate the main facilitators and barriers to an

Implementation Science approach being adhered to within palliative care settings. They found that facilities that were able to use an approach that tailored the intervention to their particular setting, as well as to the needs of their patients were more likely to find the implementation approach more feasible and successful (Moore et al., 2020). Demiris et al. (2014) had similar findings, and stated that to enact successful interventions in palliative care settings, consideration of the implementation methods need to be considered from early on in the process, not as after thoughts. They stated that using an Implementation Science approach to palliative care programmes means that steps can be taken to prevent unintended negative consequences of under-researched interventions, and can help interventions stay effective over longer periods of time (Demiris et al., 2014).

2.7 Research Objectives

The aim of this project is to make suggestions for the development of a patient-focused education programme through the lens of Implementation Science theory and through gaining the perspectives of patients and staff at the Hospice the programme will be developed for. The specific research objectives are as follows:

- To evaluate what patients see as important within a palliative care education programme;
- To evaluate how Hospice staff members see an education programme aimed at patients as being successful;
- To incorporate both patient and staff members voices within an Implementation Science framework;
- To establish the parameters of an effective palliative care education programme within an Implementation Science framework and make recommendations on how the OCH can create a best practice programme for patients within their service.

These research objectives aim to begin the process of a needs assessment at the OCH, within an intervention mapping framework (Fernandez et al., 2019). By conducting interviews with both patients and staff who have different areas of knowledge, the needs of a collective group can become apparent, ensuring that the eventual intervention developed by the OCH is meeting the needs of a wide range of patients within the Otago community. The needs assessment also aims to uncover what patients actually want out of such an intervention, so as to ensure that the development of the programme can address these desires in a way that aligns with best practice literature. Beyond the needs assessment, this research also begins to move into stage two of the intervention mapping process, by making recommendations about the potential direction and outcomes for the development of a patient-focused programme (Fernandez et al., 2019). By conducting a thorough literature review, and linking this literature back to the findings of the research, this thesis will attempt to link best-practice with patient outcomes, to ensure that strong groundwork has occurred for the future development of such a programme.

Beyond the Implementation Science framework, this research aims to listen to both the people who receive and provide palliative care education. The reasons for this are twofold.

Firstly, only those who have undergone palliative care treatment can genuinely answer the question of what is truly important to patients in an education programme themselves and their family/whānau. It is important to capture the patient voice so that this viewpoint can be authentically communicated to a broader audience. This is particularly important within the research space, as hearing the voice of traditionally unheard participants is integral to improving outcomes for these groups.

Secondly, it is important to hear the voices of those who provide palliative care education. This is because those who create and deliver the education programmes will have knowledge about both the content and practicalities of delivering a programme through OCH. This is important within an Implementation Science context, because the purpose of creating a programme in an Implementation Science framework is to create evidence-based, best-practice education material. Hearing the voices of those who deliver the education programmes will allow an understanding of what delivery methods work within these forums. There will also be a sense of the material that can be effectively facilitated within these spaces, and how to facilitate the discussions effectively to improve implementation outcomes.

It is clear that these two groups, those who receive and those who provide the education workshops, may have different goals or desires. To sift through these complexities, it was decided that qualitative research would be the most appropriate research method for this project. I will now move to discussing the methodology and methods for this study.

Chapter 3

Methodology

3.1 Introduction

As noted in the literature review, this study aimed to use an Implementation Science approach to determine recommendations for a patient-centred palliative care education programme to be developed through the OCH. To do this, the study explored opinions and views of both patients and OCH staff members. This background lent itself to a qualitative methodological approach.

This chapter will explore the theoretical background of a qualitative research approach, and outline the particular methodology chosen for this project. There will also be a discussion on the methods of recruitment of participants, how data collection was undertaken, and the ethical considerations related to this. Finally, Braun and Clarke's (2006) approach of thematic analysis will be outlined in relation to the current research.

3.2 Qualitative Research

A qualitative research approach is one that uses a variety of philosophies, and as such can be difficult to precisely define (Guest, MacQueen, & Namey, 2012; Hennick, Hutter & Bailey, 2010). This research approach draws from the experiences of individuals and how they interact with the world around them in various ways, through research techniques such as long-form interviews, focus groups, photo-voice, biographies, and various other approaches (Hennick, Hutter & Bailey, 2010; Merriam, 2002). A key aspect of qualitative research is that of giving participants their own voice, and to ensure that their perspectives are transferred into the research process and outcomes (Willig & Rogers, 2017).

3.2.1 Qualitative Research and Palliative Care Research

Payne (2007) states that "qualitative methods are among the most useful and frequently used methods in palliative care research" (p.139), because of the depth they give to patient voices. Lee & Kristjanson (2003) also state that qualitative methods are appropriate in palliative care research because the research method "allow[s] an in-depth investigation of unique care experiences and can be designed to suit the available energy and resources of the subjects" (pg. 15). This, in particular, is key to the current research project. The patient participants in this project were all experiencing life-limiting health issues. A qualitative approach to uncovering their realities and insights was the most appropriate research approach as the unstructured interview format was able to respond to any energy limitations that the participants had, while limiting negative outcomes for palliative care participants. The patient participants also noted that they valued being a part of something that meant they were giving back to other patients through their voices being heard. This prioritisation of the patient voice was a key reason the qualitative approach was chosen.

3.2.2 Interpretive Paradigm

One aspect of qualitative research that will be drawn on within this research is the interpretive paradigm (Hennick, Hutter & Bailey, 2010; Willig & Rogers, 2017). This paradigm emerged as a response to the dominant positivist paradigm of the 1970s, which focused on objectiveness and research that was free from researcher bias and opinions (Hennick, Hutter & Bailey, 2010). The interpretive paradigm seeks to respond to this positivist method by prioritising the idea that there is no single objective truth, and that researchers do inherently bring subjectivity to their studies, and in turn have an influence both on the data creation process and the interpretation of the data (Hennick, Hutter & Bailey, 2010).

3.2.3 Reflexivity

Reflexivity is a concept that arose as a way for researchers to maintain rigor and trustworthiness within qualitative research (Dodgson, 2019). It is a way for researchers to acknowledge their own role within the research they conduct, both in the data gathering phase and during analysis (Symon & Cassell, 2012). Berger (2015, p. 220), writes: “Researchers need to increasingly focus on self-knowledge and sensitivity; better understand the role of the self in the creation of knowledge; carefully self-monitor the impact of their biases, beliefs, and personal experiences on their research; and maintain the balance between the personal and the universal”. The researcher must be aware of their own role within the research, and what this might bring into the analysis of data from participants (Dodgson, 2019).

I addressed reflexivity during this research project by doing the following. During the whakawhanaungatanga process in interviews, I addressed my status as being both an insider and outsider to the OCH. I am an outsider, because I do not work at OCH, and therefore do not have any control over decisions the organisation makes. The intention for making this clear to participants, particularly patients, was so that they felt comfortable talking to me as someone separate to a paid employee of the OCH who may be providing healthcare and support to them. I also acknowledged my insider status, that is as someone who volunteers for the OCH within their biography team. Disclosing this helped my rapport building with staff participants in particular, but also seemed to put patients at ease as well, that I knew some of what OCH offered and how it works. This mix of insider/outsider status helped me during the analysis process of this project, as it meant that I did not have particular pre-conceived notions about a possible education programme that a staff member might have, and so was able to analyse the data with the fresh eyes of someone outside of the organisation. I also made notes after interviews, to ensure that I was processing the interview content and being responsive to what was raised by the participants. This process of keeping notes meant that I was able to adapt questions, or pick up on threads raised by participants in future interviews, to garner a wider range of views on certain topics.

3.3 Ethical Considerations

Researchers must take care to ensure that ethical principles of research are followed. This is particularly important within qualitative research, where participants might give highly personal answers to questions asked of them. I will now outline some principles of ethical conduct that I addressed and abided by within this study.

3.3.1 Voluntary participation and the right to withdraw

Participation in this study was voluntary for all participants. No participants were pressured to participate in the research. For patients, the programme was mentioned during a Kōwhai education session, and family members took the study information home to the patients. These patients were in contact with my on-site supervisor, Denise, who facilitated the exchange of contact details. It was the patient's choice whether or not they investigated further after hearing about the study. For staff, information about the study was disseminated at a staff meeting, and the information sheet was circulated via email. All participants were informed that they had the right to withdraw at any point in the research up until data analysis had been completed. This was included within the consent form provided to participants, and was verbally communicated before the interviews. No participant received financial remuneration for participation.

3.3.2 Informed consent

The information sheet I provided to all participants contained all necessary information about the project and what would be asked of participants. Participants could ask questions directly to the researcher before agreeing to participate, and all relevant information was revisited verbally before the interviews commenced. Participants could, and did, ask questions about the research which I answered before the interviews commenced. Participants were reminded that they could contact me or my supervisors if they had subsequent questions regarding the research.

3.3.3 Coercion

This concept was an important one to consider. Both patients and staff members interviewed for this project may have felt an obligation to participate because of either the care they were receiving via the OCH, or because the Hospice was their employer. I made clear to participants at every opportunity that participation in the research would not adversely affect their care or employment, and that participation was completely voluntary. I was not involved in any care of patients, which removed one element of perceived coercion, nor was the researcher an OCH staff member at any time. As noted, I also have not previously dealt with any research participants in my voluntary work through the biography service.

3.3.4 Confidentiality, privacy and anonymity

I took steps to ensure the maintenance of participants' confidentiality. All interviews with participants were conducted individually, so as to maintain privacy. The raw data was seen by myself and my research supervisors, as well as a private transcriber paid for by myself. The raw data was stored electronically on a password protected laptop. Consent forms were stored in a locked cabinet that only I had access to, and were scanned to my password protected laptop. During transcription and analysis, pseudonyms were used for participants, and any identifying information (workplaces, partner's names, etc) was removed from the data or anonymised.

3.3.5 Minimisation of harm to participants and researcher

For patients in particular, it was important to minimise potential harm from the line of questioning. Although the research was not designed to provoke emotive responses, it was understood that these responses could happen regardless. I was aware of referral pathways to counsellors within the OCH, and arrangements could be made for any patient to see a counsellor if need be. All patients were already well supported by OCH, which helped minimise the risk for ongoing harm. I was also well equipped to deal with any emotions that arose in participants during the research and could respond empathetically in the moment if any such feelings arose. If staff members showed distress during the interviews, there was a clear pathway as to who they could debrief with following the interview. No emotional distress was reported during or after interviews. I paused patient recordings midway through interviews on two occasions to address mild physical discomfort that arose – needing to briefly rearrange to a more comfortable sitting position. This was resolved quickly on both occasions and the interviews continued. At the start of the interview I reminded participants that they could decline to answer any question during the interview; no participant chose to do this.

The interviews with OCH staff members were conducted on-site at the OCH, in a private meeting space during work hours. The patient interviews were conducted in their homes, so my on-site supervisor and I put in place agreed-upon safety measures. My on-site supervisor knew when and where the interviews were taking place, and I texted her following each interview to let her know it was complete and that no issues had arose that Care Coordinators should be aware of. Space was made by my on-site and academic supervisors for me to debrief if necessary, although this was not utilised as the interview process was proceeded as anticipated.

3.3.6 Ethical Approval

Ethical approval was sought from the Massey University Human Ethics Committee, and was approved on October 18, 2022. OCH gave written approval and support for this research to go ahead.

3.4 Data Collection Part One: Interviews with Patients

The first part of this research focused on hearing the voices of patients who had opinions about the development of a patient-centred education programme.

3.4.1 Recruitment

As previously mentioned, recruitment for this research was primarily conducted through a discussion about the research at a Kōwhai session. The research was outlined to my on-site supervisor who relayed this to family members who attended the Kōwhai session. My on-site supervisor liaised directly with interested patients, and distributed the information sheet about the research. Once patients confirmed they would like to take part in the research, my on-site supervisor passed their contact details on for me to liaise directly with the participants. I then contacted the participants to arrange the details of the interview and to discuss the finer points of the research with them in more depth, to confirm suitability. Before the interview was conducted, participants were given the opportunity to ask further questions before signing the consent form (Appendix 2). Myself and my on-site supervisor made clear to participants at all stages that there was no requirement to participate and that they could withdraw at any time with no consequences to their care or employment at OCH.

I revisited the content of the information sheet at the interviews, and answered any questions the participants had at the time of the interview. I confirmed again their option of withdrawing without negative impact before the interviews began, and participants were made aware of their right to withdraw their data up until the point that analysis was completed.

3.4.2 Selection and Sampling

I chose participants as a mostly homogenous sample, so as to gain an understanding of a particular subgroup (Suri, 2011). The particular subgroup focused on for patients was those patients who had a family member attending the Kōwhai programme. The aim was to interview participants who had specific knowledge to contribute to this research, and because all participants had a family member engaging with the Kōwhai programme, there was an assumption that there would be a base level knowledge about what the OCH offers in the education space, as well as being able to reflect on what aspects would be useful for patients in an eventual patient-centred programme.

The intention of the research was to interview six patients, which would allow for a diverse range of views, but also keep the scope of the interviews manageable within a Master's level research. The aim of this portion of the research process was to gain an insight into the needs and desires of patients within the education space, so that the OCH can include and consider these when creating their patient-focused education programme.

Due to limitations with the length of time for recruitment, three patient participants were interviewed. Small sample sizes are considered appropriate within qualitative research (Braun and Clarke, 2013), and a smaller group does fit the purpose of this research, which is intended to be a starting point of viewpoints for the OCH to draw from in future programme development. Taking into consideration the limitations of the duration of a Master's research project, three patient participants was viewed by myself and my supervisors as acceptable for the study.

3.4.3 Eligibility Criteria

The first criteria was that patients were well enough to be interviewed. This was assessed with the collaboration of my on-site supervisor, who liaised with community care workers who work directly with patients under the OCH's care. Only patients who were physically well enough to participate were given information about the project.

The second criteria was that the participants had a family member currently attending the Kōwhai family-focused education programme. This meant the participants had some knowledge about the existing programme, and so could comment on various aspects that may or may not be useful for patients.

The third criteria was that the participant had not been interviewed by the researcher as part of my role in the OCH biography service. This was to avoid any suggestion of power over the participant, or that the participant would feel like the data was being reported back to the OCH. There would also be no influence from a previous rapport built in the different interview setting.

3.4.4 Data Collection

I conducted individual interviews at the patients' home. I chose a one-on-one interview as it would be less physically demanding than a focus group, and also allowed for each patient's voice and opinions to be heard in full, rather than navigating a group dynamic. The interviews themselves were able to be paused as necessary, in response to the participants' comfort levels. As noted, two interviews were paused briefly for physical comfort reasons. The time of day was decided by the participants themselves, to minimise interruptions and maximise energy levels. Each participant was interviewed once only, so as to minimise the coordination efforts which went into scheduling the interview.

Semi-structured interviews (SSI) were conducted to encourage participants to share their thoughts and opinions openly (for full interview schedule, see Appendix 3). Questions were intended as a loose guide for the conversation, rather than something the researcher stuck to rigidly for each interview. The intent behind the interviews was to be guided by the participants, so as to understand their viewpoints. This is an advantage of the SSI approach, which is often used in research in which the participants are encouraged to put forward their own views to which the researcher can respond to fluidly (McIntosh & Morse, 2015). Using this method, I could delve further into particular responses participants gave during the interviews to gain a deeper understanding of their viewpoints, and explore tangents that arose from the discussion.

Examples of the initial open-ended interview starter questions included:

- What do you see as the benefits of adapting an education programme to be suited for patients?
- What are some key aspects that you would like to see included in a patient-centred Hospice education programme?
- What content do you think is not relevant for a patient-centred programme?
- Do you have any views on the length of the sessions and how many there should be, and the frequency of their occurrence?
- What do you think about running the programme via Zoom, during Covid restrictions?
- Is there anything else you'd like to tell me about how you think the programme could run?

I reviewed each interview after completion, and used the points raised to inform subsequent interviews. This meant that the research process was not static and instead was evolving as the interviews progressed, depending on areas that were raised, or not, by previous participants.

Interviews lasted between 35 minutes to 60 minutes. Interviews were conducted with the participants alone in two cases, and in the final patient interview the patient requested that his wife stay for the interview. Two men and one woman were interviewed. All participants were over the age of 60. Two participants were New Zealand European, and one from an Asian background that is not specified here due to identifiability reasons.

The interviews were audio recorded and transcribed by a professional transcriber paid for by the researcher.

3.5 Part Two: Interviews with Employees

The second part of the research was focused on gaining the views of those who work in the palliative care field at the OCH and have knowledge and insight into what a patient-centred programme could look like through first-hand conversations with patients during their time at OCH. All interviewees in this section had been working at the OCH for at least three years, with many having worked at OCH for over a decade. Many had either attended Kōwhai at some stage, or had spoken to patients about their viewpoints on an education programme.

3.5.1 Recruitment

Staff members were notified about the research project at a staff meeting, and were given a copy of the information sheet (Appendix 1) via email. Participants were given the opportunity to discuss the project with the researcher before booking an interview time, to answer any questions they might have before agreeing to participate in the research. Prior to the interview, I went through the information sheet again briefly with staff participants, and participants signed the consent form (Appendix Y) after this overview. It was made clear at all stages of recruitment that the participants could withdraw from the research at any time, and that their participation or withdrawal would not have an adverse effect on their employment status or treatment within the OCH.

3.5.2 Selection and Sampling

As in Part One, participants were a relatively homogenous sample, as they all worked at the OCH for a long period of time. Despite this, efforts were made to recruit a range of OCH staff members to include a variety of perspectives. Staff from the education team, the community care team, spiritual care team, and nursing team chose to participate in the research, and were interviewed about their particular views.

As with patients, the intention of the research was to interview six staff members, which allowed for a diverse range of views, but also kept the scope of the interviews manageable within a Master's level research. In total, by the end of the data collection period, seven staff members had been interviewed, which was considered acceptable for this study by myself and my supervisors.

3.5.3 Eligibility Criteria

Those interviewed for this portion of the research had to work for a Hospice organisation. They also had to work directly with patients and/or family members regularly within their roles. The aim of this portion of the research was to gain the perspectives of those working on the ground alongside patients. These viewpoints also served to illuminate what is realistic within the palliative care education space, and brought forward practical considerations that patients may not have considered, as they do not work within the OCH, nor have most of them sat in on the existing Kōwhai programme.

3.5.4 Data Collection

Interviews were conducted with staff members at the OCH, in a private meeting room. The interviews lasted between 30 to 60 minutes and were conducted within work hours for staff. The interviews were structured very similarly to the patient interviews, in both content of the questions and as SSIs. Extra prompt questions specific to staff included the following:

- How do you think we can meet different cultural needs for patients?
- What considerations should be taken in facilitating an education programme for patients?
- What facilitation techniques do you think would be useful when working with this population?

The aim was to identify any areas for education that patients did not identify, and to identify specific facilitation techniques that would be applicable to this particular population.

The interviews were audio recorded and transcribed by a professional transcriber paid for by the researcher.

3.6 Transcription

The recordings of the interviews were transcribed in a way so as to capture pauses, uncertainties, particular idioms or turns of phrase used by participants, and other quirks of their speech. This way of transcription was important for the type of qualitative analysis chosen, qualitative description, which emphasises participants' voices without distortion by researchers (Doyle et al., 2020). Although the interviews were transcribed by a paid transcriber, I took the time to become familiar with each interview and read through each transcription while listening to the interview, so as to get a feel for the authentic 'voice' of each participant.

3.7 Data Analysis

I have chosen two analysis techniques to base my data analysis around. The first is qualitative description, and the second is thematic analysis. Both will be discussed in the current section, before the results and discussion are presented in subsequent chapters.

3.7.1 Qualitative Description

Qualitative description (QD) is an approach researchers use in healthcare-focused research (Kim, Sefcik, Bradway, 2016) to gain a deeper understanding of participants' thoughts and experiences (Doyle et al., 2020; O'Brien et al., 2019). There is also an emphasis on asking participants to describe their thought processes, perceptions, or experiences, so that a richer analysis can occur (Doyle, et al., 2020; Ireland, 2022). Qualitative description is a particularly useful approach for developing interventions, as information can be gathered from participants about their viewpoints for the intervention development (Kim, Sefcik, &

Bradway, 2016). This makes the approach reflexive in nature, and researchers are able to explore various theoretical options depending on what arises during the interview process (Kim, Sefcik, & Bradway, 2016). The sample size of QD studies is usually lower than other types of study designs and the richness of experience that researchers can draw from participants is viewed as highly important in QD research (Lambert & Lambert, 2012; Magilvy & Thomas, 2009), which is in keeping with my own sample size.

Magilvy and Thomas (2009) state that the purpose of QD is to "describe the participant's lived experience" (p.299). Lambert and Lambert (2012) agree with this assessment, going further to add that researchers using this framework are not aiming to manipulate data to fit a pre-selected set of variables. This was an integral goal of my interviews with patients. A key aspect of my research was establishing what patients themselves wanted from an education programme, not what they anticipated other patients to want. I asked about what would be useful for them, in relation to their own experiences and journeys with their illness, so that I could gain a deeper understanding of the particular context they were each bringing to the research.

QD is often used in tandem with a thematic analysis approach, which I employed in this study (Kim, Sefcik, & Bradway, 2016). The reason for this closeness in the analysis approaches is that QD presents qualitative material in a straightforward, naturalistic way, with the participants' voices expected to be centred within the analysis process (Killam & Heerschap, 2013). Sandelowski (2000), writes that QD researchers "stay closer to their data and to the surface of words and events", as compared to other analytical research approaches. Doyle et al. (2020) adds that analysis in QD research is "data driven" (p.448) and without pre-conceived philosophical research perspectives. Thematic analysis aligns with this method, as it is an approach that also encourages researchers to minimise conjecture and transformation of data during the analysis process, rather researchers should stay grounded in interpreting the data that is produced in a way that is congruent with their participants (Colorafi & Evans, 2016; Kim, Sefcik, & Bradway, 2016; Vaismoradi, Turunen, & Bondas, 2013).

3.7.2 Thematic Analysis

Thematic analysis was used to analyse and interpret the results of the semi-structured interviews. I followed Braun and Clarke's (2006) six phases of thematic analysis to interpret the interviews. Thematic analysis is a useful approach to qualitative research, designed to guide researchers in drawing out themes and patterns from within data (Braun & Clarke, 2006; Maguire & Delahunt, 2017). This methodology is seen as a flexible approach to data analysis, and is intended to go further than simply summarising the data produced during the research; rather it goes further to interpret and understand the data in relation to the research questions and aims (Braun & Clarke, 2006; Guest, et al. 2019; Maguire & Delahunt, 2017). Finally, thematic analysis presents findings in a way that is digestible and accessible (Braun and Clarke, 2012). This is important, as the results of this study will be made available for the OCH, and so need to be easily understood and applicable to their work.

I followed Braun and Clarke's (2006) framework for thematic analysis, which involves six phases. I will outline these phases and describe how I worked within each phase to analyse the data for this thesis.

Phase One: Familiarizing yourself with your data

The first phase of a thematic analysis involves the transcription of the interviews, reading over the interview transcription, then noting down initial ideas about the data (Braun and Clarke, 2006).

As noted earlier in this chapter, each interview was transcribed by a paid transcriber. The transcriber transcribed the interviews verbatim, to ensure that the voice of each participant was accurately captured. Place-holder noises such as 'umm' or 'hmm' were transcribed, and pauses were noted by the transcriber. Once I received the transcribed document, I then checked each one for accuracy by listening to the original interview while reading the transcription. Any corrections were made to the transcripts at this point. After this data cleaning occurred, I read all interview transcripts multiple times, while making brief notes of my initial ideas for data analysis.

Phase Two: Generating initial codes

The second phase of thematic analysis is to begin coding the data systematically, while highlighting areas of interest and sorting the data into groups as this coding occurs (Braun and Clarke, 2006). This can be undertaken manually or through with the assistance of a software programme (Braun and Clarke, 2006).

I conducted this initial coding manually in the Word documents the transcriptions existed within. I did this by highlighting relevant codes in different colours, while making comments about what piqued my interest about particular data as I coded. I coded the patients and staff members separately initially, then noted similarities and differences for both of these groups once initial coding had taken place.

Phase Three: Searching for themes

Phase three of thematic analysis involves bringing codes together to make overarching potential themes, and finding all data relevant for each theme (Braun and Clarke, 2006).

I did this by reviewing my colour coded system, and using this to form the first round of themes. Most themes had sub-themes that emerged as I undertook this process, which I colour coded in related shades of the initial theme. I reviewed my initial notes and made further additions to these comments so as to gain a firm understanding of where my themes were situated within the data.

Phase Four: Reviewing themes

The fourth phase of thematic analysis involves two levels. The first is a review to ensure that the themes work in relation to the initial extracts. The second level is to repeat this, in relation to the data set as a whole (Braun & Clarke, 2006).

This phase was an ongoing process for me, as I reviewed all chosen extracts and ensured that a pattern was apparent. This process meant that I removed some of my initial extracts as they no longer fit within my themes. I also re-checked my data set as a while, to ensure that no relevant data had been missed during phase two of this process.

Phase Five: Defining and naming themes

This fifth phase involves continued analysis to refine and define the themes, and the overall story that the data analysis tells the reader. Each theme and sub-theme is named (Braun & Clarke, 2006).

I wrote notes about each theme, to make sure that each theme told a coherent story about the data within it. I ordered and re-ordered the data within each theme, to make sure that the data was presented in the most meaningful way possible for the research.

Phase Six: Producing the report

Phase six involves writing up of the results, providing analysis in relation to the research aims (Braun & Clarke, 2006). This will be undertaken in the following Findings chapter.

Chapter 4

Findings

The following findings are a combination of patient and OCH staff member perspectives. Quotes will be identified by pseudonyms, with a note identifying whether the participant is a patient or staff member. Findings will be presented alongside literature and some interpretation of quotes, and further analysis will occur in the following Discussion chapter.

Seven main themes emerged from the research, most with their own sub-themes. These themes were:

1. Knowledge about palliative care and OCH

    1.1 Stigma about Hospice care
    1.2 Stigma about death and dying
    1.3 Health literacy

2. Support and community

    2.1 Support focus vs education focus

3. Patient-specific education content

    3.1 Practical education content
    3.2 Relationship dynamics
    3.3 Coming to terms with death and dying

4. Workshops being conducted with carers or separately

    4.1 Different needs for patients and carers

        4.2 Benefits of some sessions being attended together

5. Cultural considerations

    5.1 Current demographics at the OCH
    5.2 Being culturally responsive

6. Physical and emotional barriers physical and mental needs

7. Group logistics and dynamics

4.1 Knowledge about palliative care and OCH

Patient knowledge about palliative care, health literacy, and Hospice services more broadly, emerged as a topic of interest from research participants. There was general agreement across both patients and staff members that many patients do not have good knowledge about palliative care, or Hospice services in general, which can be a barrier to accessing healthcare, but also to attending any subsequent patient education programme.

4.1.1 Stigma about Hospice care

The patients that were interviewed for this project had knowledge about the services OCH provides, perhaps because of their partners attending the existing Kōwhai programme. However they all spoke about how they felt palliative care patients in a general sense were not particularly knowledgeable about OCH services:

> *Well probably the common perception of the hospice is that the end of nigh and in fact it's not. (Roy, patient)*

> *And Hospice, uhm, because more so on these Facebook pages, uhm, for bowel cancer, uhm, there definitely is stereotypes there for most people. Hospice means just suddenly end of life care (Mary, patient)*

These comments raise an interesting discussion, as all patients interviewed seemed to think they had a higher understanding than other patients of what OCH care involves and what services are on offer. This might be a feature of their carers having attended the Kōwhai programme, but could be a case of over-estimating their own knowledge in relation to others. This tension will be explored further in the following Discussion chapter.

4.1.2 Stigma about death and dying

Death and dying is a topic that is heavily stigmatised within Western society (Steinhauser, et al., 2000). There are a variety of reasons for this taboo, and one is that since death and dying most commonly occurs in hospitals in today's society, death has been hidden from public view (Carrieri, Peccatori, & Boniolo, 2018).

Participants referred to this stigma, particularly in relation to OCH:

> *I think people hear the word hospice, and then they think "oh, I must be really bad, I'm dying". And so they just think of this as a place to come and die (Donna, OCH staff member)*

> *You know a lot of people they think palliative care, they think the focus is on the dying, there are still people who think it's about ending somebody's life, euthanasia so that's a constant thing we've got to be aware of (Kathy, OCH staff member)*

These quotes, and Roy's and Mary's from the previous sub-theme, represent, a deeply held fear in New Zealand society of death and dying, and the decaying process up to death. This means that the fear extends not only to patients, but also to patients' family members, carers, and their support networks more broadly. The complexities of what this means for patients is discussed further below. This stigma that Donna and Kathy refer to prevents patients from wanting to engage with OCH services. These quotes also show the importance of breaking down some of the stigma that surrounds not only death and dying, but hospice care itself.

> *It's also just letting them know…and supporting them to live life to the full you know, not just giving up and curling up in a corner saying "I'm dying" (Kathy, OCH staff member)*

Kathy's quote illustrates a clear benefit of engagement with OCH. Not only is the focus of Hospice engagement not solely focused on end of life, Kathy goes further to state that in actuality, the Hospice provides an avenue for patients to live their lives to the full, whatever that might look like for individual patients. Kathy expanded on the fear that many patients have about the hospice, and what a patient-centric programme could offer:

> *you know for many people are still terrified of the hospice, "the place to go to die, you know, go in there, you know" and so I see programmes like this as a chance to help break down those fears (Kathy, OCH staff member)*

Debbie (OCH staff member) agreed:

> *I think that they think a Hospice is somewhere to die, if they know anything about it at all. Uhm, and I, don't think they realise, you know, that, you know, that, it used to be 70% of our patients would come in for symptom management, and return home.*

Kathy and Debbie both pick up on fears that patients have regarding OCH services, which aligns with the Atena et al. (2022) study that showed upwards of 60% of patients did not have a strong understanding of palliative care and what can be offered. Patients interviewed for this study showed an understanding of the care OCH provides, separate to the stigma they felt other palliative care patients hold regarding Hospice services:

> *I think hospice, I mean hospice obviously is doing an excellent job helping out sick people in the old age. I mean there are a lot of other things than just being sick. Sometimes some people simply can't do things and hospice will help out you know, providing carers and people like that and that was just marvellous, that's really good (Irving, patient)*

> *I'm presuming that Hospice will be a bit more gentle and uhm, not sort of gentle as, more towards making life comfortable as opposed to doing "medically" things… So, that's why I've booked into Hospice, early I thought, I'll get it done. I'm signed up, so that if at some stage, middle of night or something, I do want help, it's there already, and I know it's there just to, uhm, make the rest of, uhm, my life, as comfortable as possible. And for me, I'm pr-prioritising quality of life over quantity of life. (Mary, patient)*

Irving was the patient most engaged with OCH services, and had attended the Kōwhai training along with his carer. He spoke with confidence about OCH, and he appeared to be the most sure of all the patients interviewed about what the OCH offered, due to his high level of engagement with their services. This level of engagement and knowledge shows that there is potential for attendance at an education programme to lead to de-stigmatisation of Hospice level care.

As well as improving patient knowledge of OCH, participants also made recommendations regarding education material that focused more on emotional care surrounding death and dying, which in turn may reduce stigma for patients:

> *Grief and loss, because they're also grieving and they are often worried about their family and I think in some ways that might be a slightly different topic for them where they're worried about their families and how their families are going to cope when they've gone. Addressing those kind of fears which is slightly different to what they family's fears and worries about grief and loss might be so I think grief and loss is definitely you know a topic that adds value. (Kathy, OCH staff member)*

> *I think, making meaning about the place of, of illness in your life, and it's, it's more of a spiritual kind of, uhm, session? Whereas [pause] something that I have come across in terms of the work that I do, is people making meaning of [pause] the illness from a psychological perspective in terms of "what does it mean" [pause] "what does it mean when my symptoms get worse?" and people immediately go to "oh the disease is going to get worse, that means I'm dying". And that kind of psychological angst that comes along with making those connections (Eileen, OCH staff member)*

Eileen's quote in particular highlights the needs of patients to be aware of their illness, not only on the physical level, but the emotional consequences of symptom management as well. This relates to Smalley et al.'s (2022) study that highlights the need for patient confidence in their symptom management – if patients are more empowered about how to manage their symptoms through education, then they will be less alarmed when they experience worsening or new symptoms. The purpose of the education provided by the OCH could be to limit that 'psychological angst' Eileen describes regarding symptom management. Through this education process, patients could become more at ease with the concept of death and dying, and have more understanding about what symptom changes mean for their ongoing treatment.

4.1.3 Health literacy

Many staff members talked about patient health literacy being very poor and how the OCH addresses this by working with patients about when to take medications or how to do so in a way that works for them. Debbie said:

> *So they think, well they've got a problem, they'll take a pill, that should be all gone. And they're surprised when it returns…Uhm, yeah, there's lots of levels of illiteracy that affects many of our patients. And, uhm, that education is just continually ongoing. Uhm, and we're always going to have patients who kind of, uhm, they go rogue with their pills [laughs], they just kind of do their own things. Or, I particularly remember one patient who just put all their pills into one container, and would just kind of take any old colour for whatever, you know, not understanding that they could actually do themselves some harm. (Debbie, OCH staff member)*

This echoes a study by Bund and Du Plessis (2015) regarding patient desires for HIV and AIDS treatment. This article talked about one patient detailing how she stopped taking her medication because pills would often be different colours and she was never sure how much to take. When this patient was given the opportunity to ask questions and learn about the correct way to take her pills by a health professional, she was able to do this with ease.

OCH has an opportunity to add real value in addressing misconceptions about medication for patients within an education context. Debbie states:

> *the more they understand about, uhm, their disease and how that's affecting their body, and the medication that they're recommending, uhm, that they understand when it needs to be taken… you know, 'cause we want to encourage living. You know? And getting them to understand that it's okay to take some pills beforehand, to get on, so it minimises the risk of those, uhm, symptoms exacerbating. (Debbie, OCH staff member)*

My research emphasises the real, inherent and deeply ingrained barriers that OCH faces in successfully educating patients, however, the literature affirms the real value of patients having access to education to improve their health literacy and subsequently their health outcomes. Smalley et al. (2022) established similar findings, that education targeted around self-management of illness helped empower patients and was useful for their health outcomes.

4.2 Support and Community

Against the background of stigma associated with death and dying, participants referred to the loneliness and isolation that patients may experience during their dying process. Participants strongly identified that support and community is a key benefit for patients, which may be found in and created by an education group. Both patients and staff members held a range of views about whether the programme should be education focused, support and social focused, or both. There were also discussions had about the value of building shared experiences with other patients, to stave off some of the loneliness and isolation that patients feel in their diagnosis. Patients appeared to gain benefits of sharing their experience with not only those patients who shared their same diagnoses, but also with patients who were in palliative care more broadly.

Patients referenced the loneliness and isolation that they may experience, in their wider support networks and even with family members and close friends:

> *And one of the difficulties I've had, not difficulties, but, I've been around with this longer than most people…and I've looked well right through the time. For me to lose my hair was actually, uhm, [pause] it wasn't the sympathy, but you know, it helped people remind me that this is part of my life that I'm going through. So to have friends that will talk to you, uhm, say 'how are you going?', be interested in what your treatment's doing, and how things as a whole person, whereas some people just don't want to know anything about it, and you sort of feel, yeah. So you want to have people who understand. (Mary, patient)*

Mary spoke to the benefit that she would receive by being around other people who knew and empathised with her, that death and decay is not always visible. Implicit in patients attending a programme would be that they are dying. Mary suggests that patients would provide understanding and support to each other, because the fact that they are dying need not be spoken. An education programme may effectively accelerate the intimacy and support process. Irving, the only patient interviewed who had attended the Kōwhai programme alongside his wife, agreed about the support patients found within an education context:

> *We could hear [group member] A saying this and [group member] B saying this, C saying this and the way I did it was like this which part of [the support]. (Irving, patient)*

Staff members elaborated on these patient viewpoints:

> *I think that there are symptoms which people find scary…the symptoms that some patients [pause] they think they're the only people in the world that experience them. And when they get into a group, and they're provided with some information, and, some coping strategies, and, sometimes a bit of knowledge is quite empowering. (Linda, OCH staff member)*

This quote demonstrates the non-overt support that patients can receive from hearing other experiences and perspectives. Hearing that they are not the only one to be experiencing their symptoms can build community within the group setting, which can help mitigate some of the isolation that patients might otherwise feel. Eileen elaborates:

> *So, I guess I've seen first-hand what the [pause] the, the benefits that patients got out of it? And, for me, that was, uhm, [pause] being able to be around other people who are in the same situation? Because, uhm, family and friends might have, might, might be sympathetic towards what's happening to you, but they don't really have an understanding of what it's like to be living your life? And, other people who are in a similar sort of situation do have some healthy respect, uhm, so, being, being able to, to connect with other people who have some understanding of what's happening to you, I think that was huge, for, uhm, people that I talked with in the past. (Eileen, OCH staff member)*

Both the staff and patient perspectives illuminate how important the shared experience is to patients – patients will also gain an understanding that they are not alone in experiencing their symptoms and they can learn from one another's perspectives. Even though OCH statistics indicate that 75% of patients supported are through cancer diagnoses, common symptoms across dying patients including breathlessness, fatigue, weight fluctuation, pain, and mobility, would mean that even patients with different diagnoses may find benefit from this community (Otago Community Hospice, 2022). Even with a different symptom expression, this benefit and support could be at a minimum that they are sharing the process of death and dying with the group setting.

A staff member added another perspective about managing patients' complex feelings about their illnesses:

> *And so people feel like a fraud, and, you know, I think being mindful of - and this is even the groups together or the groups separately – being mindful of uhm, people's fierce anxieties around their illness progression with other people, who may be more advanced in their, ah, illness trajectory. (Jennifer, OCH staff member)*

This quote emphasises the importance of being responsive to patient needs and emotions that might arise in a forum like this. However, it is impossible to avoid all negative feelings that might arise for patients, despite practitioners' best effort. We see this in the results of Villarreal-Garza et al.'s (2022) study, which found that 13% of patient participants found the education programme presented to them as causing them some level of distress, but 97% of the group still rated the programme as useful or very useful. By managing these dynamics around illness progression by engaging in open conversation, attempts can be made to mitigate discomfort within patients, but even if discomfort occurs it does not appear to be a barrier to benefiting from and engaging with an education programme.

4.2.1 Support focus vs education focus

There was a range of viewpoints raised regarding whether or not the eventual programme should have a support focus, an educative focus, or a mix of both. Participants held mixed views on this, with patients and staff differing in their approaches. Roy, a patient, stated the following about education being the focus, clearly valuing the social side of what a programme could offer:

> *And to some people that might be tedious but if there's a bit of a break and a bit of a chat, you get to know people a bit more socially would be better" (Roy, patient)*

However, Debbie, a staff member raised a point about previous iterations of patient support groups:

> *In the very early days of the Hospice, we did have a day Hospice. So that's, patients would come in, uhm, have the option of coming up to three days a week…It was aimed at patients, but uhm, that stopped, because it became, people became sicker and found it more difficult to come. And said, definitely socially they loved it, uhm, and then of course, it, there was a funding issue…So, yeah, and you know, I, I don't know whether it, and this is an interesting ethical thing, is it the Hospice's role to fill that social side of things? Uhm, I-I think personally not? I think our funding, we have to be canny with it and clever, and uhm, it probably, I would err on education because of that, because money is not, there is not an unlimited amount of it. (Debbie, OCH staff member)*

Debbie's comment emphasises the difficulties that organisations such as OCH, face in relation to funding, and how considerate and deliberate they must be in accessing and using their funding. A programme with a strong education focus is most likely going to be easier to receive funding for, as there will be clear benefits to patient outcomes and illness management, beyond the social side of the programme, which could turn into more of a peer support service, rather than educative in nature. The education programme that could be developed by the OCH will also be significantly shorter than a full day, three days a week programme, that Debbie outlined.

Debbie also references the limitations that funding may impose on an organisation like the OCH. These limitations narrow the scope of a prospective programme, and Debbie suggests that having to curate programmes and activities that are within the scope and ambit of the Hospice's Kaupapa and allocate funding responsibly, by asking whether it is the Hospice's responsibility to provide a purely social or support avenue, beyond an educative resource.

4.3 Patient-specific education content

Another theme that emerged was the question of what educational content would be most beneficial to patients who undertake the eventual programme. Participants had a range of suggestions regarding what could be included, from practical content, to content more focused on relationships and emotion management. Underpinning these suggestions was a distinct theme that the scope of content must be patient-specific to be most impactful.

4.3.1 Practical education content

Staff members identified some practical content that they have found useful for patients:

> *often the lawyer session is really popular [for carers]? Uhm, because that tends to be something that we don't talk about in public, you know, writing wills, trusts, uhm, enduring power of attorney, I think that's poorly understood by general public. Uhm, and they're all important to well-being and health. (Linda, OCH staff member)*

> *I guess, some of them would be advanced care planning. It might be the legal matters, talking about wills and EPOAs because often people are reluctant for example give up control by signing an EPOA even though they are not but reframing that for them as a maintaining control when you can't speak for yourself, the same with advanced care planning. So I see that would be really, really valuable. Medications, having an understanding of the medications because so often people are scared to use some of the medications because they're worried about the side effects or they're worried about addiction or they simply don't know about them. There's a lot of common concerns that we talk about at Kōwhai and I think a lot of patients would find that valuable (Kathy, OCH staff member)*

These practical topics would be useful for patients, as increased knowledge will help patients feel empowered in their own care (Chan et al., 2022; Smalley et al., 2022). The practical topics could help give patients a sense of control over the things they can make decisions about, and guide them in their thinking about what they would like for their end of life care.

4.3.2 Relationship dynamics

Beyond the practical content, participants raised the importance of education about more personal content, such as how patients may navigate the nature of relationships changing as their illness advances. This can include the topics that are discussed, such as talking about end of life and dying, which as previously referenced, has a deeply ingrained stigma surrounding it.

Both staff members and patients noted in the interviews the complexities with navigating the relationships between carers and patients, and discussed how to empower patients to prioritise their relationships:

> *Something about maybe relationships? Because I think relationships can sometimes take a bit of a back seat, you know? Like, everything becomes about, everything becomes about the cancer, or the COPD, or whatever. Everything becomes about the next doctor's appointment, the next hospital appointment, the next physio appointment. Everything becomes about "when is this pill supposed to be taken", and "oh, am I assessing, are they in breathless, are they in pain?" you know? And maybe the, I mean, in the, in the work that I do, I've seen that the relationship can sometimes fall down the list of priorities? That's, that's important, it's important in terms of their ongoing wellbeing, in terms of their ability to cope as things get more challenging. So, maybe something about relationship, you know? Protecting that relationship or nurturing that relationship might be something that we add? (Eileen, OCH staff member)*

> *I think patients should be asked you know, what happens if your carer does this so and I might say, well I don't like it and why don't you like it blah blah blah you know. Because sometimes I felt really bad sometimes in the morning, [patient's wife] would probably like to help me and I sort of said "no, no, no". It hurts her and it hurts me you know having to say that but I just didn't feel that I was up to it sort of thing so*

> *that is a bother to me and maybe some discussions on that with the patients…may help, both carers and the patients. (Irving, patient)*

Irving felt that it was important to have a topic that strengthened patients' communication skills so that, for example, Irving could feel better equipped to explain to his wife why he might not be responsive to her wanting to help him, particularly if he's feeling sore or not up to it. This is another reason why symptom knowledge and management is so important in an eventual programme, because it gives patients the language to explain what is going on for them at any given moment.

Eileen's point about the illness taking the forefront of the relationship between patient and carer is also pertinent. There may be some room for discussions on grief and loss about that change in relationship between the patient and their family member. As well as grief and loss, participants felt it was important to have conversations about how to give focus to the relationship between patient and family caregiver, even amongst symptom management and coming to terms with death and dying.

4.3.3 Discussing death and dying with loved ones

Even more personal, participants spoke to, was when family members feel able to talk about those difficult topics together, but ultimately have different views about them. This can be straining on relationships which are already strained with stress-associated grief. In relation to funeral planning, Mary, a patient, described having conflicting views about her funeral with her family due to religious differences:

> *I've been trying to organise stuff, and I've asked [pause] somebody to take my funeral. We've talked about that and [my family] sort of, ah, think, it's going to be full blown religious funeral. And it's not type of thing. It's just that, you know, this person does have, uhm, a faith as well. I mean, other things, [pause], I suppose, uhm, and my daughter mentioned, 'what about somebody else?' (Mary, patient)*

Having the space to discuss and plan for what they want their funeral to look like may help patients like Mary to feel firm in their convictions when dealing with family members who want different things. Funeral planning is covered in the existing carer programme, and so to create a patient-focused version would be possible for the OCH, while also noting that patients might bring significantly different views and emotions to this conversation.

A staff member spoke in further detail about the tension between family and patient choices:

> *It's interesting cause I'm working with a family at the moment, and I've had one opportunity to talk to this lady by herself, like there's always family members. There's always somebody in the room and that one time, I think the daughter had gone into the kitchen so and her husband was away. And she started to open up to me but there's never, and started talking about what she would like to happen when she dies. And then more visitors came and then that moment was lost but I have never been able to get that back again. Like uhm so that might be a really good opportunity like having those conversations like separately from yeah. Cause I'm really conscious of the fact that she is dying but we aren't able to have those conversations (Donna, OCH staff member)*

Donna identifies that having a patient-centric programme is important, in that many patients do not feel comfortable having end-of-life conversations with their family, or even in front of them at all. Donna states that opening up these end-of-life conversations in front of family members can be difficult for patients, and some may benefit from having these conversations in a separate space, away from their family. Beyond feelings of discomfort, this might go further into patients feeling pressure from family to do things in certain ways, as Mary discussed in her earlier quote.

Through the dying process, patients become increasingly vulnerable at different stages. This fragility means that providing patients with tools to effectively communicate with and navigate relationships with their loved ones, is even more important, to allow them to maintain those relationships whilst also being empowered through their illness.

4.4 Workshops being conducted with carers or separately

Participants held differing opinions on whether or not the programmes should be separated between the carers and the patients. Some participants felt strongly about the programmes being separate, as both carers and patients may have things they want to discuss in the group setting without the other person there to hear. Participants also noted that the needs of patients and carers are potentially quite different; there may be some crossover such as during sessions such as moving and handling, or advanced care planning, but there are also some aspects that were viewed as quite separate, such as grief and loss, and self-care. This suggests that there is clear benefit in having some sessions separate and tailored specifically to patients on one hand, and carers on the other. Fundamentally though, again we see the impact of the stigma of death and dying as being a reason to have some sessions together.

4.4.1 Different needs for patients and carers

Literature shows how important attending education programmes is for patients' quality of life (Papadakos et al., 2021; Stephenson et al., 2021), In this respect, it is integral to make sure the programme delivery meets patients' needs and allows them to speak freely without feeling inhibited or limited. Patients and carers have different needs in an education space, which many participants alluded to in their interviews, particularly in regard to the existing carer programme. What this means in practice, is that there is a strong need for patients to have their own space to speak freely about their experience, without having to balance their carers needs at the same time.

Sharon discussed why it might be important for carers to have their own space to talk, and her quote also illuminates why this might also be important for patients:

> *the caregivers did seem to, ehm, relinquish the floor to the patients [in a joint education setting]… And when you think of, how much space and time and energy the patients take up in the caregiver's life, that probably isn't [pause] an unreasonable window into their lives at home either, you know? As a caregiver [they] don't ask you as a patient to give me things, or to do things for me, or, so, the demands are one way, the voice is kind of one way… A good insight into how it probably is. 'You're the*

> *sick person and I will defer, and I will allow, and I will tolerate'. (Sharon, OCH staff member)*

This quote is interesting because it demonstrates how difficult it can be to balance the needs of both patients and caregivers. In this project, the research ambit relates to a patient education group being formed, and the intention is that the programme is therefore patient-centric. Sharon's quote represents the deep tensions at play though between a patient's health needs and outcomes, and those of the caregiver. Although Sharon's quote relates to carers, the meaning can be applied to patients as well. If carers defer to patients in an educative space, then neither party is able to put forward their true feelings, as patients have previously stated that they want to know more about how to speak openly with their carer. We must consider this critically to ensure that the separate programmes prioritise patient and care voices in separate avenues.

Eileen agrees:

> *I get that it needed to be separated in this way, so that, ah, carers could have a place where they were able to, 'cause when, I think carers are also wanting to protect the people that they love? And the people that they are looking after? So they might not be able to ask some questions when they are around? So I do get that that was, you know, that was needed, to separate them. But I mean, what I think what's happened is that, uhm, patients haven't had that same [pause] community of, uhm, of support I guess... So it's good for, for them to have some of the attention on themselves as well, and addressing their particular needs. Because let's face it, uhm, both carers have needs and patients have needs. But they don't have the same needs. You know? (Eileen, OCH staff member)*

What these quotes illuminate is that it could be difficult for both parties to get their voices truly heard in an education context if patients and carers attended together. There might be an effect of silencing both groups if they do not feel able to speak freely, which would not be the intent of the programme. As it stands, patients have little spaces to voice their thoughts and feelings about what it going on for them, particularly with others who are going through similar journeys.

Self-care was isolated as one discussion topic in particular that needed to be kept to separate groups. Linda commented that patients can become overly invested in protecting their carer, that they neglect fundamental aspects of looking after themselves:

> *Maybe the self-care discussion needs to be separated? Because, the patients get, can get so involved in trying to, trying to protect the carer, uhm, that they forget about looking after themselves, so that the reverse, they're worried, they're worried about their wife, or their partner, uhm, [pause], so… perhaps separating that session? And giving the carer the opportunity to talk about how difficult it is for them might be useful. (Linda, OCH staff member)*

Participants also discussed the difference between patient goals and carer or staff member goals, and recognised that these goals may be in direct conflict with each other. In that instance, in an already vulnerable population, the literature referenced earlier around increasing resiliency and advocacy skills in patients becomes important. Patients need to be equipped to communicate their goals and feel comfortable with expressing these when met with different views of carers or staff members. This is demonstrated in the following quote:

> *Often the, as nurses and doctors…we talk about…figuring out what the patient's goal is. And sometimes their goal is not necessarily the same as ours, but their goal is the most important...So their goal is usually to get home, or it might be to maybe do a bucket list sort of thing, be well enough to do that. And so, then, our goal is to get their symptoms managed well, so that they can do that…So they get as much quality time as they can. (Debbie, OCH staff member)*

Debbie's quote emphasises the need to understand what patients want, and how these needs can be met in an educative space. A key part of this can be empowering patients to accept their death and give them permission to feel ready to die and leave their loved ones, even though carers in particular may have the opposite goal of wanting to keep the patient alive.

As well as education of emotional empowerment for palliative care patients, there is a sense of relief that comes from having a shared understanding with their carer:

> *I mean, I'm a patient, I can't really ask [patient's wife] to do things that I used to do myself before and it's sort of partly I suppose, from my point of view, partly involves some pride that I'm disabled now in a sense you know, but if I said that [patient's wife] will say "no, you're not", so this is the sort of area that I think could help particularly if the Kōwhai is for both carers and patients particularly so that at least we both will understand "ah" so that's what's happening and this is what we should be thinking about as far as the carers are concerned and the carers, vice versa will sort of be like "oh, yeah okay" so we've got to be both resilient and tolerant and I don't know whether one can actually be both (Irving, patient)*

Mary talks about the pressure she feels to stay alive at all costs, which is an idea that could be teased out in an education group setting:

> *Sometimes just some help can just make, uhm, things just come, just get things sorted like that, means you can face a bit more, maybe treatment or something like that yeah. But uhm, you know, keeping alive at all costs is [pause] hard. (Mary, patient)*

These quotes illustrate a variety of tensions that patients hold. Debbie's quote illuminates how the OCH staff attempt to view the patients' goals as the most important, and adapt their goals to the patient's expectations. This tension can be difficult in an education space, where facilitators are attempting to balance the needs of multiple patients, while still being aware that individuals may be struggling with particular goals or expectations. Mary's quote is a topic that need to be discussed in a patient-only group, so as to minimise the guilt patients might feel about not sharing their carer's view of staying alive, no matter what.

4.4.2 Benefits of some sessions being attended together

Kathy identified the potential of a knowledge gap as an important reason to have both carers and patients engaging in an education programme:

> *I like that, bridging the gap because when one person knows the information and the other doesn't, I know, I'm quite aware that, you know, sometimes people go home from Kōwhai and sit down and go through the handouts and this is what was said*

> *today and they said this and they said that and that's really great but not everyone has that ability to do that or has the person open to receiving it, so. (Kathy, OCH staff member)*

Kathy raises an important point. For many reasons, in addition to the emotional toll of taking care of their loved ones, some carers may have limited health literacy or the ability to recall and relay information to their loved one. Even more complex is that patients may not be receptive to hearing the information as presented by their carer. Both aspects highlight the need for a patient-centred programme. Further to this, the expectation to share the education information with patients may add an extra burden to some carers, or vice versa for patients, particularly when considered with earlier quotes around prioritising patient/carer relationships outside of the patient's illness.

Linda noted that attending the programme together could be a way to encourage patients to attend:

> *Yeah, I think, that sometimes, for the patient, having a caregiver with them can be a bit inhibiting? Perhaps? And, [pause], but then on the other hand, it can [pause], be a way of getting a person to attend, so, it could be that then, there are some, there might be some sessions, where families, caregivers and patients could attend together in some sessions, where they're not together but perhaps held at the same time, in perhaps a similar, the same or similar venue. (Linda, OCH staff member)*

Roy had a similar view, and considered the complex emotions patients might be feeling about attending the education programme with or without their carer:

> *You know some people would be concerned if they were separated from their carers or vice versa. Others would prefer perhaps to be in a situation where the programme would allow them to communicate concerns which they wouldn't to raise with their carer or the carer with the patient so again, it's got to be addressed carefully as to which category those people fall into (Roy, patient)*

One approach to overcome this would be to run some sessions together and some sessions separately for patients and carers. Participants noted that practical sessions such as moving and handling, advanced care planning, and funeral planning, for example, could be good sessions to combine with carers and patients. These sessions were identified by interviewees as having less emotion attached to them, and so there would not need to be as much consideration paid to managing each other's feelings. Staff members suggested that creating two separate programmes where there were sessions that came together for some topics could be a logical approach:

> *That, that you have the carers' programme and you have the patients' programme, and then there's a couple of sessions where there's crossover? Uhm, because sometimes, it is, it is good for people to hear what their partner's saying. That they may not feel able to say, in the privacy of their own home, or in their own home, or to be able to grieve together, or to be able to, you know, tackle some particular topic together? (Eileen, OCH staff member)*

> *I think there would be sessions were you could bring patients and caregivers together, and they might not be the caregivers of those patients, but I think there would be benefit in some of the sessions, but there's also benefit in them being very separate for the majority of the sessions. (Sharon, OCH staff member)*

There is much to consider when deciding which sessions could be combined and which should be kept separate. Even the quotes above contradict some of the earlier quotes in this discussion – the previous section discussed the importance of having space to have difficult conversations separately, and these quotes talk about being able to create the space for patients and carers to grieve together. These tensions will be further explored in the next chapter.

4.5 Cultural considerations

Participants brought up cultural considerations at many points throughout the interviews. Sub-themes included current OCH demographics, why a culturally accommodative programme would be beneficial, and how to apply different cultural needs with an education programme.

4.5.1 Being culturally responsive

Staff at OCH talked about the struggle to boost Māori and other cultural groups involvement with their service:

> *We're a predominantly Pakeha organisation. We've tried for 16.5 years to engage, eh, the local iwi, the wananga, and we've made inroads in the last probably four years? Ehm, and I think this organisation is viewed as somewhere for middle class white people to come? So we're trying to dispel that. And we have a Kaimanaaki, and we're hoping that we can make that difference. But I don't know that, ehm, for Māori especially, they have, ehm [pause], they have quite traditional ways of dealing with death and dying… I think they probably [pause] maybe even do death and dying a bit better than us? So it would be lovely to have their input into the Kōwhai. (Sharon, OCH staff member)*

> *Like, uhm, it's, we were talking about this the other day actually, that we have very few Māori families who actually come into the in-patient unit. I'm sure that our care coordinators probably do see many, and, also, very few Pacific Islander or Asian. And those families tend to keep them at home. (Debbie, OCH staff member)*

Sharon and Debbie's comments reflect a desire to engage more with Māori patients and communities when it comes to Hospice care. Engagement with iwi and marae is a good way to start this process (Te Ora, 2019), as Sharon notes. It is clearly important for the staff members at OCH that their service is seen as something broader than catering only for middle-class white patients and their families. Debbie's quote highlights the importance of having flexible care options for Māori and Pacific patients, which is backed up by literature that shows that Māori patients and whanau are more likely to want to undertake palliative care within their own home, wherever possible (Te Ora, 2019; Muircroft et al., 2010). Any education programme that the OCH develops needs to be cognizant of these different needs, and could aim to start by being culturally responsive to Māori clients from the beginning, so as to engage this group early in the process. This also ties into addressing stigma and misconception about Hospice care, because most patients that are under Hospice care are cared for and die in their own home. Addressing these misconceptions could help patients from diverse cultures feel more comfortable in accessing the services on offer, if they knew they could stay within their own home. Sharon elaborates further on why this is important:

> *The demographics is quite small, yeah, but we, ehm, [pause] so it's not about the uhm, Māori who are in the community, it's the amount of deaths, and what they're dying from that interests us more, because they have got, an, ehm, you know, a higher statistical mortality and, and, for the diseases that we would commonly look after, so cancers and respiratory, being two, and renal, the third, you know, there's are quite high prevalence in the Māori population? So there's more complexity, because they're younger usually, you know? So they could be the breadwinner, or they might be, ehm, the, main eh, head of the family, you know, so, yeah. (Sharon, OCH staff member)*

This quote raises an interesting consideration. Māori patients are statistically more likely to be suffering from the top diseases that the OCH deal with than non-Māori, and they are also more likely to die from these illnesses (Gurney et al., 2020; Ministry of Health, 2022). This could mean significant changes could be made to a programme targeted towards this group, because the struggles of younger patients will be a lot different to those struggles of those who are experiencing illness later in life, which is not in-keeping with the OCH's current age demographic (Otago Community Hospice, 2022). This means that there could be a different approach taken to meet the specific needs of a younger population in the palliative care space.

4.5.2 Varying cultural needs

Irving felt that in collectivist cultures, such as many Asian cultures, care is done collectively for patients and he found the way that New Zealanders engage with Hospice services quite jarring:

> *I mean like "wow" this is something that in my culture it just doesn't happen right because the family would take care of that patient. (Irving, patient)*

Irving raises an interesting tension, as he is still engaging in Hospice services who support him and his wife to feel able to address Irving's care in their own home, while the OCH provides specialist care when needed. This links back with the misconceptions about the Hospice, as patients from collectivist cultures might not realise that they can access the specialist care, over and above the at-home support they already receive from their family members. This at home care for whānau members can come with a toll, however, and those supporting patients to stay at home experience higher levels of stress and the impact of grief is higher on these family members (Te Ora, 2019). This is an important consideration to be made when considering the programme development, as part of the programme might be around exploring what patients need on a cultural level and how the OCH can begin to bridge this gap for patients and whanau. Kathy stated:

> *So how could we get greater Māori involvement? How could we have this better fit for Māori health models…What might it look like and I think it's the obvious group to start with, is the Māori culture because it's clearly our leading group within our society but I think having done that, there would be lessons learned from that that we could then evolve by going to perhaps the Chinese community or the Malaysian or the broader Asian community and say "look, this is what we're doing, this is what we've learned, this is what we've evolved, what are your thoughts?" because we do have quite a multi-cultural society in Dunedin…and you know if we have a, say, 30% Māori [population], why do we only have, I don't know, 2% Māori on the hospice programme, what are we not getting right? That's a really big question. (Kathy, OCH staff member)*

Finally, the importance of a patient programme meeting the needs of Māori clients through the pillars of Te Whare Tapa Wha (Durie, 1984) was emphasised:

> *Well, so much of an illness is about the physical health you know and I see the Kōwhai as being one place that we can really consciously address those other three pillars (Kathy, OCH staff member)*

OCH staff are clearly thinking about the needs of a diverse range of patients and are aware that by providing culturally accessible and appropriate education, they are more likely to engage with a higher number of patients which will in turn lead to better health outcomes for patients.

4.6 Patients' physical and emotional barriers

Participants discussed a range of both physical and mental/emotional needs that patients might have prior to entering a palliative care education programme. These considerations ranged from how to maintain their identity separately to their diagnosis, the reluctance that loved ones might feel in accepting the death of the patient, and the tension between what patients' goals are and what staff members' goals are for them.

As for the practical and physical considerations, participants had the following to say:

> *I think that we should only be considering people for the Kōwhai programme, those who are still, uhm, more on the independent side, so still mobilising, still uhm, still physically able, uh, to get in the car, get out of the car, walk into a building, sit for an hour and a half, or two hours, and, uh, participate. (Linda, OCH staff member)*

> *if people are unwell, this is something that probably would need to be offered earlier, whereas people often think they don't need the Kōwhai programme until later and then sometimes it's too late. I think a patient programme would certainly need to be offered earlier (Kathy, OCH staff member)*

> *I guess it's like the difficulty for people, if you are having a bad day. And then you have to pick up sticks and come in here for example, or uhm trying to arrange transport as well. And I guess like, there's a lot of people out there that don't have anybody…but it's the organisation of getting, physically getting there and if you are feeling really grotty as well (Donna, OCH staff member)*

> *Physical obviously as I said, you know. I could still come and attend and I would like to think mentally, I'm still okay as well so that I could actually involve myself in the discussions and I have so that's a plus for me, but there are patients who physically can't be there although mentally be good. (Irving, patient)*

These physical considerations are important, as it represents real barriers that need to be taken into account by an education provider. Further, patients may need to feel that the programme will be worth the effort – potentially the physical exhaustion, the pain, the breathlessness, and the nausea from increased movement – for them to attend. This highlights the importance of early intervention, as attending earlier on in the illness progression, will make managing those physical symptoms more straightforward. Linda backs this up in her quote above about the length of the programme, when she states that patients should meet a minimum standard of wellness to attend, so that they can participate comfortably in the session without the programme taking a physical toll on them while they attend.

Irving illuminates the physical/mental divide that patients might face when choosing to attend. Patients might be mentally competent, but physically unable to attend the programme with ease, so an effort to bring patients on board early in their diagnosis will be beneficial. This relates again to the Smalley et al. (2022) article about patient symptom self-management. If patients are successfully brought on board to an education programme early, then they are more likely to be able to self-manage effectively, because they have built skills at an earlier stage of their illness progression. Alternatively, if they are too physically unwell to attend, they limit or even forego any potential benefit that might have been available had they attended before their illness advanced.

Some further potential emotional barriers to attendance were illuminated by patients and staff members:

> *people who have an abhorrence of death or talking about terminal illness so that would be the challenges for those people and that would need to be dealt with very carefully in some cases. Other cases, just come out and talk about it so again, depends on the individual (Roy, patient)*

> *I think the biggest one probably is that, uhm, to acknowledge the fact that you're going to die. Some people, uhm, different circumstances can do that…Uhm, [pause], mainly the, having to accept that this is going to happen I think, is going to be the biggest thing? Uhm, and whether you're scared of it or not. So, yeah. (Mary, patient)*

As demonstrated by these quotes, the reluctance to talk about death and dying is a significant and potentially distressing barrier for some patients, and might be enough to deter them from the programme. Sharon adds to these considerations, talking about the impact on patients if this potentially distressing topic is not managed effectively by the programme facilitator:

> *Yeah I think, specifically for, I think there would have to be a high sort of ehm, degree of safety. I mean, mental, eh, psychological, emotional safety. So whatever, ehm, you know, these are triggering topics, and it's alright to be [pause] ehm, able to say anything to anyone, but actually, we're not talking about me, it's not my death we're talking about you know, and so I think you would, you would need to, we would need to, ehm, be very careful that we had, not just what is the topic, but how, what is the reaction, how [exhales], I've had some horror stories of ehm, you know the consult that has gone horrifically wrong, and caused huge emotional toll on people afterwards. (Sharon, OCH staff member)*

This emphasises the importance of a strong and well-trained facilitator or education provider, which will be discussed further in the following chapter.

4.7 Group logistics and dynamics

There are a variety of practical points to consider when deciding how to structure a patient-centred programme. Participants noted the importance of a strong facilitator, there were discussions about regular attendance versus a more ad hoc attendance approach, the length and frequency of the programme, and the benefits and drawbacks of reattendance to the education programme.

Having a strong facilitator was an area of note for participants:

> *I think that's a good idea, but I think it needs to be moderated and mediated [laughing] because, you have, again, you have very strong ideas about, uhm, "oh if you take this vitamin C injection, that's going to, you know, cure you" or, whatever. And, I guess, that, that thing people do of "I know how you should be living your life" [laughing] or "you should be doing these things", I think it needs to be facilitated so it is actually supportive and doesn't place more pressure, uhm, or, ah, result in sort of, uhm [pause] ah, some more unhelpful ideas being circulated [laughing]. So I think, I think it does need to be moderated. (Eileen, OCH staff member)*

> *There is a skill around how you encourage conversation, how you manage to get people to make the space safe, for you to speak about what you want to speak about? And there is a real art to that…especially when you've got different coping styles, and all these things, around how, being in a group environment, like I say, how you make that space safe? For people to speak honestly before we got into the more intimate, deep conversations (Jennifer, OCH staff member)*

Eileen's point about misinformation being spread in these workshops is pertinent. Although it is important that patients are allowed to chat and share support and experiences with each other, it is integral that incorrect or harmful advice not be accepted within the group. This links back to the importance of empowering patients to be able to self-manage symptoms (Smalley et al., 2022) – if they have the incorrect information, then they will not be able to self-manage correctly. This will be revisited in the Discussion chapter to provide further context. To ensure that the group receives the correct information, a session could be dedicated to the self-management of symptoms. If patients have queries that may stem from misinformation, the facilitator can direct them towards reputable sources of information. Jennifer comes from the angle of a facilitator having to hold space for difficult conversations to occur within a patient programme. In both examples, the facilitator of the workshop will have to be responsive to patient needs and adaptive to group dynamics, which is exactly why a strong facilitator is needed to navigate these conversations. The specific skills of the facilitator will be explored more in the following chapter.

Most participants were in agreement that the current run time of 2.5 hours for the carer focused programme was too long for patients. Interviewees suggested 1-1.5 hours, depending on the health of the participants attending. Some participants noted that 1 hour blocks could allow the sessions to be focused on one topic in depth, which could lead to more robust conversations, rather than changing between multiple topics over a session.

> *Weekly is a good thing. 2.5 hours [pause]. See I think there'll be some patients who will be perfectly able to cope with that. And some who might find that, find that a bit long. I think 2.5 hours is a bit long for patients. (Eileen, OCH staff member)*

> *Different people have different staying power in these things, some people two and a half hours of lectures is quite a long time, other people, if the subjects are interesting*

> *and they might find it riveting and just think the time flashed past so it depends on the topic, it depends on the level of interest of a person and that depends on the patient involved, the wellbeing or the health of the patient involved as to how long they should be and indeed, what aspects they should cover so it's very hard to generalise quite frankly (Roy, patient)*

Irving brought a different perspective to these discussions, which is important to consider as he was the only patient interviewed who had been attending the Kōwhai programme alongside his carer:

> *The way it runs at the moment is okay with me. Once a week, two and a half hours, I think anything less than that would not allow, it would preclude actual discussions you know, but it would just be a one way thing, but so far, what we have witnessed is that there are discussions. Everybody talks about their problems and it's open so one talks about the wife was sick and the sort of things that, funny things that she wanted and so on. Another one talks about his mother. Another one talks about her father with a problem of "he doesn't talk to me. He doesn't tell me anything. I have to find out myself", all that sort of thing (Irving, patient)*

Irving clearly finds value in the longer time provided within the carers programme, and sees clear limitations if the time for a patient programme was shortened. He feels that a shorter run time would mean that deeper conversations may not be able to occur in the same way, and the group would not get to know each other as well as they do through the Kōwhai setting. As discussed earlier in this chapter, the support aspect of the education group seems to be an important factor in patient attendance, so to limit the opportunity for this discussion to occur could be a barrier to patient attendance. Shorter session times also means that patients may stand to gain less information from the programme, rendering it not as effective as the Kōwhai programme.

Linda argued that having a 'pick and mix' type structure for the sessions could be useful for patients:

> *I think it's good that patients are told they can pick and choose which sessions they would like to go to. (Linda, OCH staff member)*

> *I think pick and mix is okay. I mean, yeah. You'll always get some people that will go to everything, and some people that go to one or two. (Linda, OCH staff member)*

A pick and mix approach removes some of the previous barriers to attendance that were previously discussed. If a patient does not feel well enough to attend a session one week, then they can rest assured that it will run again in due course for them to attend again. Further pros and cons of this approach will be explored in more depth in the following chapter.

Participants also discussed the idea of repeat attendees to the programme and some of the risks of allowing this to occur. Debbie stated:

> *Uhm, I do know that uhm, in the past, and I did have, a patient make a complaint, so in the very early days, she uhm, she, there were a couple of patients who had been to the programme several times? So they were very comfortable with the programme, and they had quite strong opinions, and she didn't feel like it was a safe place, to be able to talk, so yeah. Some people might feel more comfortable talking with other patients, because they feel those people know. (Debbie, OCH staff member)*

Debbie's quote highlights the risk of re-attendance for group dynamics. If patients are coming to the programme multiple times, this can start to have an effect on others who are attending, because the repeat attendees will know significantly more than them. This can lead to domination of group discussions, which alienates other participants from feeling like they can contribute. This reiterates the importance of having a strong facilitator for the patient-centred programme, as they may need to manage some of these dynamics within a group. The facilitator must feel confident to redirect repeat attendees if they are dominating conversation. Repeat attendance also gives the impression that the group is support, rather than education focused. If someone is attending multiple times, it may be that they need more support in the home, rather than in a group setting.

Participants were not in unanimous in this view, however:

> *Uhm, because, I think it's important that you don't shut the door on people, just 'cause they've been before, doesn't mean they know everything. 'Cause their*

> *trajectory has changed, and so what I needed over here when a person is relatively stable, and now we're in a dip, and the information I need here is very different, and the conversations are very different. So, I'd never ever close doors to people either. I think it's really inappropriate. (Jennifer, OCH staff member)*

Jennifer felt strongly that the door should never be shut on repeat attendees, because their illness progression may have changed and they may need to hear the information again so as to take different meaning from it, now that the relevance has changed for them in their illness progression. However, if a patient's illness progression has changed that significantly, a more personal one-on-one intervention might be more appropriate than a group setting, regardless of their desire to reattend the programme.

The next chapter will discuss and analyse these findings in more depth, and will include a discussion about how to put these learnings from participants into action with recommendations for future programme development.

Chapter 5

Discussion

5.1 Introduction

This research aimed to explore Otago Community Hospice patient and staff member perspectives about a prospective patient-focused education programme, using a semi-structured interview process. The research offered an opportunity for both groups to have their voices heard in relation to the development of such a programme, and aimed to prioritise patient perspectives in this process. Using thematic analysis, I established key themes and sub-themes to understand these perspectives. What emerged were complex experiences and perspectives, some of which led to tensions which will be discussed further in this chapter.

Participants highlighted the stigma that exists about death and dying, and Hospice care more broadly. This stigma can inhibit patients from accessing the support and community which was identified as another key theme to the research. Specific education content was highlighted as being important to participants, patients in particular, to help bridge the gap between stigma and understanding. There were rich discussions about the desire (or not) to bring patients and carers together within an education programme, and this interlinked with cultural considerations that participants raised. Finally, themes emerged regarding the physical and emotional needs that patients might have when engaging in an education programme, and discussions were had about how to manage the logistics and dynamics about these needs.

5.2 Summary of main findings and comparison with existing literature

The order of the established themes in the previous chapter was carefully considered. The themes built on each other and illustrated how a patient-centred programme could be created in the future. Although all of the main themes of this study were interconnected in varying ways, unpacking stigma was the main theme that underpinned all other themes. Stigma played out in a variety of ways throughout the findings.

5.2.1 Stigma

Stigma is quite possibly the biggest barrier that patients may face in attending a patient-focused education programme. The participants in this research stated that patients hold a substantial amount of stigma, not only about the OCH itself, but also about the idea of death and dying more broadly. This finding is supported by broader literature. Atena et al. (2022) and Perry et al. (2021) note that one of the biggest barriers to engaging in palliative care services is patients not understanding what palliative care involves and what benefit it would provide them. This literature can be extrapolated to the potential education programme when taken alongside the participant viewpoints. If patients feel that engaging in the education programme is indicative of giving up, or being close to death, then they may be less likely to attend.

This ties into other themes drawn from the interviews. One of the main benefits of the potential education programme that participants raised was the opportunity to discuss death and dying in a facilitated way. Participants specifically mentioned that death and dying is stigmatised and feared even with other patients seeking palliative care treatment. Being able to address this within a carefully facilitated group could help patients move beyond the fear that comes with their diagnosis. This refusal to see past stigma has wider consequences for patients.

Holding stigma about Hospice services means that patients may turn down opportunities to be referred to other health interventions, and by the time referrals do occur, it is sometimes too late for patients to see benefits of Hospice level care (Carrieri, Peccatori, & Boniolo, 2018). As Atena et al. (2022) noted, engagement with palliative care services early on in a patient's diagnosis leads to a variety of positive outcomes, which includes physical and emotional benefits to patients. If patients are not aware of the services OCH offer, or misunderstand them, then this will be a barrier to accessing early interventions and ultimately limit the benefits they might have received from these early interventions. A patient-focused education programme can address some of these early interventions by helping patients feel confident to engage with intervention approaches that could be of benefit to them.

5.2.2 Barriers to engagement

Participants identified a range of barriers to engagement with a potential programme that traversed multiple themes. As demonstrated by the analysis regarding stigma, the reluctance to talk about death and dying is a significant and potentially distressing barrier for some patients, and might be enough to deter them from the programme. This could be potentially addressed through targeted, positive focused interventions such as Chan et al.'s (2022) study regarding brief hope intervention. If the eventual patient intervention can be targeted towards hope, or other positive outlooks, patients might be more likely to attend, rather than fearing that they will have to confront their mortality within the group setting. However, this positive approach conflicts with some areas that participants felt were important to cover, such as grief, and education about practical matters such as Advanced Care Planning. It will be important for a future programme to find the balance between what has been borne out in the existing literature, and align this with stated patient needs from this research. Possible approaches to this tension will be explored in the recommendations section of this chapter.

Another barrier to engagement for patients is cultural competence within the programme. As shown in the findings, OCH staff are clearly thinking about the needs of a diverse range of patients and are aware that by providing culturally accessible and appropriate education, they are more likely to engage with a higher number of patients which will in turn lead to better health outcomes for patients. However, at this stage, the OCH predominantly caters to white patients (Otago Community Hospice, 2022), despite cultures such as Māori being more likely to die from life-limiting illnesses and be diagnosed at later stages (Muircroft et al., 2010)). If Māori patients in particular do not feel able to attend the OCH, this is a huge barrier in them accessing culturally accommodative care. Te Ora (2019) showed that culturally appropriate approaches have a higher rate of engagement, and so the OCH will need to create a culturally flexible, adaptive and responsive environment to break down these barriers for Māori patients and encourage them to engage in an education programme. Suggestions will be made in the following recommendations section about how the OCH could achieve this.

5.2.3 Tension with carer/patient divide

Another main research finding was the tension that arose from participants in regards to patients and carers having joint education or separate sessions. This tension was raised by both patients and staff members, and there was no clear consensus, with participants seemingly firmly entrenched on whichever side of the debate they fell on.

This tension links with many of the other themes established within this research. A key link is this theme and the theme regarding preserving the patient relationship dynamic with their carer. Firstly, some patients may feel pressure from their carer about pursuing a particular pathway in their end-of-life care, or feel guilty about making choices that do not align with their carer's desire for them to stay alive, despite experiencing debilitating symptoms or a decline in quality of life. When such complex feelings cannot be safely worked through, this may lead to greater relationship problems between patients and carers. The main question raised by participants is whether or not these feelings should be worked through in individual groups or within the same group. The benefit of having separate groups may be to preserve the relationship between carer and patient, which will often be a couple. Patients may need to have the space to vent, without feeling guilty – and vice versa. However, some participants argued that these conversations could – and should – happen in a joint session. There was some perspectives raised that the more practical sessions could be facilitated as joint sessions – i.e., ACP, moving and lifting, and funeral planning. However, some participants felt that even some of these conversations should be had separately. Funeral planning, for instance, could become a loaded conversation, and both staff and patient participants spoke of navigating difficult conversations with family members who were at different stages of the grieving/acceptance of death process.

This tension about separate or joint sessions also links into the theme of cultural considerations. One patient participant spoke of coming from a more collectivist culture in which these conversations would always be had with family, no matter how difficult the topic was. A staff member affirmed this view point, stating that having a facilitator be able to hold these difficult conversations with patients and carers is important, and that there is not any reason to separate them. In terms of New Zealand's Māori culture, having whānau involved in palliative care decisions and conversations is integral (Te Ora, 2019). In this way, it seems that having at least some sessions of an education programme combined is a major finding of this research. This potential whānau involvement within the education programme also aligns with the pillars of Te Whare Tapa Wha (Durie, 1984), by prioritising whānau knowledge and feelings, alongside the patient viewpoints. This will be explored further in the recommendations section of this chapter.

5.2.4 Quality of life

Another main finding from the research was how the implementation of a patient-centred education programme can potentially contribute to an increase in patients' quality of life during the palliative care period. Improvement of quality of life in the last period of a patient's life is a key approach taken by practitioners to improve end-of-life care (Heyland, et al., 2006; Zhang, et al., 2012).

Participants raised points that relate to improvement in quality of life, even if they did not phrase their statements using that language. Health literacy is one theme identified that could raise patients' quality of life. Both patients and staff raised during interviews that some patients do not have a strong understanding of health literacy, which could lead into poor uptake in medication usage, or taking incorrect medication. Beyond this, if patients do not understand what aspects of care will be of most benefit to them, they are unlikely to utilise the correct methods (Bund & Du Plessis, 2015). This could lead to prolonged hospital stays, or not being able to stay in their own homes at the end-of-life, both of which decrease quality of life (Zhang et al., 2012). By addressing health literacy in an education programme, the likelihood of patients making choices that will most benefit them increases, leading to greater quality of life during end-of-life care.

Quality of life can also be influenced by relationship dynamics, which was raised as another key theme by participants. Participants spoke of the impact that palliative care can have on the relationship between patients and carers; for some couples this can mean that the illness becomes the forefront of their relationship to the detriment of all else. These relationships are integral to higher quality of life for patients, which Lee et al. (2022) refer to in their study about patients in their last year of life. If patients' quality of life can be maintained, then they are less likely to have long hospital stays, which in turn improves their quality of life further

(Lee et al., 2022). This finding can be taken further by linking it with the health literacy theme. If patients are empowered to feel confident in their own health literacy, then this could potentially remove a burden that carers carry in terms of health management. This could in turn strengthen the relationship between patient and carer, leading to a stronger relationship between the two, that exists outside of the illness, which then leads to a higher quality of life.

5.2.5 Social support versus education focus

Another key discussion point from participants was the question of whether the patient-focused programme needs to have an education focus, a social support focus, or a mix of both. In terms of social support versus a purely educative support, there has not been a lot of literature written that evaluates the importance (or not) of the social side of education groups. Villarreal-Garza et al. (2020), wrote that there was an appetite among participants of their study to use the social supports offered outside of the programme, such as the WhatsApp group for patients. Participants stated during interviews for this thesis that the social aspect could be something that will evolve naturally if patients want this to occur, but that it should not be the focus of the programming provided by OCH. This will be explored further in the recommendations section of this chapter.

An education focus for the programme also addresses potential funding approaches for OCH, which is an important factor to keep in mind. A programme that is purely social in nature is harder to prove a need for, and so may struggle to receive funding to enable it to run, a point raised during the interviews for this thesis. A practical, educative approach also meets the needs of patients in other areas, such as quality of life, breaking down stigma that patients feel, and planning for end-of-life. An educative approach can also empower patients to feel confident in self-managing their symptoms, a key area of patient wellness (Smalley et al., 2022). This means that providing patients with the correct information can help them feel more confident in the area of symptom management, which in turn contributes to a higher quality of life, the importance of which was covered in the previous section of this discussion. A purely social focus means that these nuances may not be explored, or may be delivered in ways that are inaccurate or do not focus on building confidence and skills within patients. However, Prevost et al. (2019) found that cancer patients in particular benefit from education focused programmes that give them opportunities to share their experiences and have conversations with others going through similar journeys. This is integral for the OCH, who predominately support those living with cancer (Otago Community Hospice, 2022). On the whole, a combination of education and social aspects was advocated for by participants in this research.

5.3 Recommended directions for the development of a patient-centred programme

There are many considerations to keep in mind when implementing a patient programme at Otago Community Hospice. The following recommendations are based on a combination of the findings of the earlier literature review and the findings from the participant interviews.

As already discussed, there were many considerations put forward by the research participants regarding how to destigmatise OCH services for patients. One major recommendation was that running these workshops at the Hospice itself makes the Otago Community Hospice feel like a less daunting place to visit. This concept is echoed by van Aalst (2013), in her thesis that looked at patient and family voice in palliative care, and by Macleod et al (2012). Hospice care is still perceived as a grim and unknown place to go, and is seen as the ‘final stop’ for many patients, despite this often not being the case (Macleod et al., 2012; van Aalst, 2013). Patients in van Aalst’s (2013) research found that even just visiting the Hospice made a lot of these concerns disappear. This is one potential benefit of a patient programme. If the programme was run on-site, then patients are able to visit the Hospice in a non-threatening way. They will also meet Hospice staff while undertaking the programme, which removes another barrier for patients. By recalibrating their understanding of the Hospice, they may be more likely to utilise other services that are offered by OCH, leading to better healthcare outcomes.

Further to this, by gaining an understanding of what services are on offer through OCH, patients are more likely to use palliative care services on offer in the future (Perry et al., 2021). This means that breaking down the stigma associated with palliative care should be a key foundation to any future education programme that is developed for OCH. By breaking down these barriers in an education workshop, the eventual programme can be a building block for patients to begin to access in-depth, palliative care that has a benefit on their health.

Another recommendation from participants was that the programme should be kept separate between patients and carers for most sessions, with the opportunity to come together for a small number of sessions, mostly focused on practical topics. Interviewees had differing opinions on this; some felt the programmes should be kept totally separate and some felt they should be fully combined. Those who thought that the groups should be separated cited concerns about both patients and carers being able to talk freely about challenges if the other person was in the room. However, it is also important to acknowledge cultural preferences, as one patient participant raised. This patient, from an Asian heritage, felt it was important that patients and carers have these conversations together, and he appreciated the group dynamic because this provided an opportunity for people to learn from others in the group about different ways others have addressed difficulties. This also aligns with Kaupapa Māori approaches to death and dying, in that patients and whānau would not normally be separated for conversations such as these (Te Ora, 2019).

My overall recommendation is that the Kōwhai programme as it exists currently should stay separate from the eventual patient programme, in most respects. It seems that there is a desire from some patients and staff to offer the opportunity for some joint sessions. This is important from a cultural palliative care perspective, to ensure that the needs of different groups are being upheld by the OCH (Te Ora, 2019). My recommendation, based on the data, is that practical sessions focused on physical needs, Advanced Care Planning, and funeral planning would be useful to have patients and whānau combined. These sessions are not topics that would ordinarily incite strong emotional responses for most participants, however strong facilitation would be required for this, as all topics have some capacity to raise emotional conversations between patients and carers.

This leads into a broader discussion about the training of the facilitator of the patient-centred programme. Patient attendees will already be vulnerable due to a variety of factors related to ethnicity, SES, and disability, and may be at a higher risk for harm, primarily due to being near the end of their lives. They might also be suffering from health complications which could make their participation in the programme limited. The risk of an inexperienced facilitator causing or inadvertently allowing unintended but significant distress to a patient is heightened and a cause for concern. Having a facilitator that is responsive and reflexive to the complex needs of patients will go some way in mitigating potential harm. My recommendation is that a facilitator would need to be skilled in building the sessions in a gradual way so that increasingly vulnerable conversations could be had by patients, in a way that is emotionally safe for them. If OCH chooses to implement some combined sessions between patients and carers, the facilitator must be aware of the complex dynamics that can exist within this relationship, and manage participants in the programme possibly centring their partner's needs, rather than their own.

Building on the need for a strong facilitator, multiple interviewees also brought up the need for a patient programme to be facilitated extremely carefully for health reasons.. Concerns were raised that patients might bring up and share false medical information within a session. For this reason, a facilitator who was well versed in the medical sphere would be needed so that they could gently challenge or debunk this misinformation. This would need to be facilitated carefully so that the patient who shared the comment did not feel targeted by the facilitator and still felt welcome within the programme. Having the correct information allows patients to feel empowered to take steps in self-managing their illness (Smalley et al., 2022). A competent facilitator would correct any misinformation in a way that makes clear the correct medical information to all participants so as to minimise any confusion and potential harm.

This leads into a recommendation about whether or not the programme should be education or social support based. As stated in the literature review, previous studies have shown that there is some appetite amongst patients to have a social support component to such a workshop (Brooker et al., 2020; Villarreal-Garza et al., 2020). Participants were mixed about what the focus should be for the OCH programme, with arguments being made compellingly for both, as evidenced in the Findings chapter. My recommendation for OCH is that the programme be created to be primarily educative in nature, while allowing for the possibility for patients to form a more social support aspect if they would like, which may vary from group to group. There would be space for this to occur during breaks, or as conversations arise during the workshop itself. Again, this would have to be effectively managed by the facilitator to keep the content relevant and on track, while also giving patients the freedom to adapt a workshop in a way that suits their group best.

In terms of group size, there were some differences in opinion about what is an optimal size. Some interviewees thought groups should be capped as low as 4 to 6 patients, whereas others thought numbers could go up to 14-16. There was an agreement that anything over 20 is too big and that with a group of that size, intimacy is lost and patients might feel overwhelmed with too many voices in the room. Literature has shown that the optimal group size for adult learning can range from as low as four participants, to up to 16 (Mora et al., 2017). Interviewees also agreed that there should be no minimum amount of patients required for the programme to go ahead – if even one patient wants to attend, then it should still run. Based on participant preferences, along with academic literature my recommendation would be to run sessions where the group size was between 5 and 12. This number allows for diversity in viewpoints of the participants, while also being manageable for a facilitator. Anything over 12 seems unwieldy for the purpose of a patient programme, which will have components of audience discussion. This number allows all group members to have their voice heard, if they choose to do so.

Group size is also important to consider from a therapeutic or support perspective. If the programme was going to run simply as an education forum, where participants listened for the entire time, it might be appropriate to have a larger group in attendance. As stated, based on participant responses, there is not a desire from patients or staff members to run a purely education-focused group with no room for deviation. Rather, social support aspects might evolve depending on the needs each group of patients, which means that the previous considerations about group size should be taken into account so that patients are accessing the most appropriate care, and that the conversations can stay manageable for the facilitator of the programme. The social aspect could be something that will evolve naturally if patients want this to occur, and I do not believe that it is OCH's role to provide this for patients explicitly, rather this can evolve naturally from group to group. Prevost et al. (2019) showed that these social aspects do often develop in groups, showing that patients value the opportunity for sharing to occur to build a shared experience.

Another practical recommendation is how long the programme should run for. Some interviews stated that 2.5 hours, as the Kōwhai programme runs for, is too long for a patient programme, however the one patient that had attended the Kōwhai programme did not struggle with the length and appreciated being able to have time for discussion within the programme. Most recommendations were 1-1.5 hours for sessions. These shorter sessions would cover less material, so consideration must be given to whether some content from the Kōwhai programme is removed for the patient programme. Alternatively, the patient programme could instead be run over a longer period of time, i.e., 7-10 sessions rather than the current 5 week programme that exists for carers. However, a longer timeframe may not be ideal for patients, whose illness progression may fluctuate during even a 7-10 week period.

The concept of offering the programme on a 'pick and mix' basis was brought up by multiple participants as one option for delivering the programme. There are some drawbacks to a pick and mix approach, however. Firstly, having patients attend a programme ad hoc means that there cannot be a coordination with the carers course, which might create extra logistical planning for patients and carers to both be able to attend their programmes with ease. Secondly, attending workshops ad hoc, rather than over a set number of weeks with the same group means that patients may not build trust with their group. This means that they may not feel comfortable engaging in difficult or painful conversations about death and dying if they do not know the other participants in the room. Thirdly, running the programme for a set period with the same group would mean trust is built and the facilitator can scaffold the discussion in a way that meets the needs of the group that are attending, rather than the group being different in each session. Therefore, my recommendation is that the programme should not be pick and mix, but instead offered on a set basis over a number of weeks. This way, it can be designed so that that each week builds on the last, to equip patients with the best possible information and skills to manage their illness. A pick and mix approach could lead to patients only attending workshops they see as directly relevant to them, and they could miss out on integral information that would improve their quality of life.

This discussion will now move into how these recommendations can be implemented in a practical sense by the OCH, using Implementation Science to support the participant data and guide the development of the patient-focused programme. Taking an Implementation Science approach ensures that the programme developer gains an understanding about which types of interventions have *not* worked, so that patients are given the highest standard of care within this programme. Adhering to evidence-based practice ensures that patients' needs are met, because the interventions that are used will have shown positive results with previous groups.

The process model that would be most appropriate for OCH to use for developing a patient-centric programme would be intervention mapping (Fernandez et al., 2019). There are clear pathways the Hospice can take to follow the steps of this model. Firstly, the needs assessment has in many ways been completed with the qualitative aspect of this research, as it is now clear that patients will be the recipients of the eventual education and support-based intervention, and participants have described what the particular needs and desires of this group are.

With the needs assessment completed in the form of this thesis, the next step is for OCH to create the programme. To maintain fidelity of the programme, a script or outline could be created so that any facilitator could pick up the programme and deliver it with consistent approaches no matter the facilitator (Fernandez et al., 2019). Following the development of the programme, OCH would identify some potential initial patient participants for the programme to run an initial pilot delivery of the programme. During this process, OCH would be considering factors such as how sustainable the intervention is, and how they can work with wider stakeholders such the Te Whatu Ora, GP practices, and Māori healthcare stakeholders to make sure the programme has longevity for patients and is having a positive effect on for the patients involved.

Finally, an evaluation plan would be developed by OCH to ensure that the programme has been effective. This might look like a before and after test of the PaCKs (Atena, et al. 2022), and other evidence-based outcomes that show in a quantitative way that the programme has had positive effects on patients. Another recommendation would be for OCH to conduct interviews in the form of a focus group with the patients, to establish how their needs have been met through the delivery of the programme.

Running an evaluative component to the workshop helps ensure that the programme has longevity to be able to reach wider groups of OCH patients, by proving that it has a positive impact on patient wellbeing. Running an evaluation can offer firm data on which areas of patient knowledge were improved, and which areas of the workshop could use tweaking. A strong evaluation also helps in a practical sense for funding applications, which was flagged by a participant as a pressing concern for OCH. To have academic proof that an intervention has positive effects on patient wellbeing would be beneficial to garnering more funding, to run subsequent programmes, which would increase the benefit to a greater number of patients.

5.4 Avenues for future research

This was a small study conducted at a single Hospice within New Zealand. Although intentional and within the scope of the purpose of the study, the recommendations contained herein can only be applied to OCH, as they may not be generalisable even within New Zealand because of the varying ways Hospices in Aotearoa operate. Although it is anticipated that there will be crossover and relevance of human and cultural needs that would mean many sections of this research will be relevant to other interested parties throughout New Zealand, future research could focus on developing a more standardised approach to patient education delivery with Aotearoa's context.

Because of the small patient sample size for this study, only qualitative research was undertaken. With a larger sample size, a quantitative element could have been introduced, i.e., the Palliative Care Knowledge Scale (Atena, et al., 2022). A quantitative approach to future research would mean that researchers would not have to rely on patients' self-disclosure of knowledge about palliative care, and instead would have a framework to evaluate this knowledge within. Some patients in the current study seemed to be more literate in this space, but without quantitative data to support these comments, it is hard to truly know where patient knowledge sits.

Future research could dedicate more time to working with participants from Māori and Pacific backgrounds to ensure that these voices are heard first hand, rather than through staff member interpretation. This would allow more viewpoints on how to integrate the principles of Te Whare Tapa Whā throughout a patient-centred programme in a way that encourages Māori patients to feel empowered to attend the workshops. In a bicultural society such as Aotearoa, it is important to truly integrate Māori health models into health education programmes. Consultation could be conducted with Māori health advisors to ensure that these principles are embedded in the framework of the eventual patient programme. Interviewees talked about using the principles of Te Whare Tapa Wha (Durie, 1984) for an eventual patient programme. The four pillars of this health model could be used as a starting point to begin considering topics for the workshop, to ensure that all four pillars are being upheld through the delivery. This would need consultation with appropriate stakeholders to ensure that the pillars could be integrated effectively into the eventual programme.

More research could be completed into how to specifically engage men into these education programmes. As mentioned in the literature review, men tend not to engage in health education programmes such as this (Stephenson et al., 2021). Again, this could be part of a further interview process, where male patients are interviewed about their specific needs and what they would like to see from an education programme. Although specific statements regarding this topic did not arise during the interview process, considerations might have to be made about potentially splitting some of the sessions by gender, for example, to ensure that men feel comfortable speaking openly in the group setting about what they are going through. Further research could also be completed about which specific health education interventions men with life-limiting illnesses have been proven to engage with effectively.

5.5 Study limitations

It is important to acknowledge the limitations to this research project. Although efforts were made to have an even division of Hospice staff and patients, this did not bear out in the research. In total, there were three patients interviewed and six OCH staff members. A bigger sample of patient voices would have allowed for a more diverse range of opinions to form. For instance, all patients were over the age of sixty, and as such, had reflections that may differ from patients who are younger and have different life considerations.

Another impact of the small patient participant numbers was limited cultural diversity. Two participants were Pakeha, while one was Asian. This meant that there were no Māori or Pacific patient voices heard, and these demographics are ones that OCH are hoping to encourage to access their services. Hearing from a wider range of patients could have meant that different themes emerged in terms of what patients think would be useful in a palliative care education programme.

Another limitation was that all patients were relatively stable in their illness progression, and had been involved with the Hospice for many years in some instances. Although interviewing patients who were closer to end of life would have been ethically challenging, it does raise the question about what education interventions would be useful for this population, if any. By only interviewing those whose illness was stable and chronic, the voices of those who have rapid onset and decline were not heard. Future research could focus on how to work with this population in an education setting.

The final limitation for this research is that no carer voices were heard. There is a constant tension between the needs of the patient and the carer, and it may have been useful to garner carer viewpoints about how education programmes could run. The limitation is that this research is patient-focused, whereas carers are an important part of the journey towards dying for the patient, and they have agency and are greatly affected by the process of death and dying for their loved one, and how OCH can support them as carers. Further, some recommendations made in the previous section involve patient and carer programmes to have some crossover, at least for some of the sessions. This recommendation could not be actioned without hearing from carers.

5.6 Conclusion

This thesis has aimed to evaluate and make recommendations for the progression of a patient-focused education programme at the Otago Community Hospice, based in Dunedin. A thorough evaluation of existing literature focused on patient-centred education within palliative care formed the basis of how a New Zealand based programme could begin to take shape. By integrating Implementation Science into the design of the research aims, this research was able to have a strong foundation of bringing theoretical material into practice. The interviews undertaken for this thesis with both staff and patients at OCH were integral to gaining an understanding of what approaches made the most sense to implement on the practical level.

By weaving together theoretical approaches and the data from the interview process, I have been able to make practical recommendations for a patient-centred programme, that OCH can begin to develop. It is important that the principles of Implementation Science continue to be utilised beyond this thesis, into the creation of the programme, so that best practice theoretical approaches and the interview considerations can be applied and evaluated in a way that leads to the most benefits for future recipients of the programme.

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Appendix 1

Implementation Science in Palliative Care: Recommendations for Improving the Efficacy of Education Programs for Hospice Patients.

Information Sheet for Participants

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this project?

The aim of this project is to evaluate a palliative care education program through the lens of a scientific evaluation and make recommendations about how future education programs in the field could effectively meet the needs of patients.

Who can participate?

There are two types of participants being sought. First is Hospice staff members who have insight into how a patient-centred education program could be designed. Second is Hospice patients who can offer their opinions on what they would like to see from a patient-centred education program offered by Hospice.

What will participants be asked to do?

Should you agree to take part in this project, you will be asked to participate in a one hour interview in which you will answer questions about what you think a patient-focused education program designed by Hospice should look like. You may decline to answer any questions or stop the interview at any stage. Choosing to participate or not in this research will not impact on a patient's continued care by the OCH, or the continued employment of a staff member.

What information will be collected and what use will be made of it?

The researcher will make an audio recording of the interview, which will then be transcribed for research purposes. Only the researcher and her academic supervisors will have access to these transcripts. The transcripts and recordings will be securely stored and kept for 5 years. Any personal information [such as contact details] will be stored separately from the transcripts and recordings, and destroyed once the summary of the results have been sent to you.

You will be given the option to review the transcript of your interview, and correct or remove any data you provide until the point of data analysis. You will be offered a summary of the finished thesis.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study prior to data analysis being completed;
- ask any questions about the study at any time during participation;

- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- ask for the recorder to be turned off at any time during the interview;
- be given access to a summary of the project findings when it is concluded.

How can I participate?
To participate, please contact Rachel Shaw at [redacted] or [redacted] to ask any questions and register your interest.

Thank you for your time,
Rachel Shaw

If you have any questions about the project, please contact:

Rachel Shaw
School of Psychology, Massey University
[redacted]

OR academic supervisors:

Prof Christine Stephens
School of Psychology, Massey University
c.v.stephens@massey.ac.nz

Dr Don Baken
School of Psychology, Massey University
d.m.baken@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 22/28. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz.

Appendix 2

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Implementation Science in Palliative Care: Recommendations for Improving the Efficacy of Education Programs for Hospice Patients.

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read, or have had read to me in my first language, and I understand the Information Sheet. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I agree/do not agree to the interview being sound recorded.
2. I wish/do not wish to have my recordings returned to me.
3. I wish/do not wish to have data placed in an official archive.
4. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

I [print full name] ____________________________________ hereby consent to take part in this study.

Signature: _________________________ Date: _________________

Appendix 3

Interview Schedule

I intend to use a semi-structured, open-questioning interview style for this project. As such, the line of questioning will develop as the interviews progress. However, the following questions will be used as a guide to shape the interview process for both Hospice staff members and patients.

- What is your current knowledge of palliative care? What do you think patients' knowledge of palliative care is?
- What do you see as the benefits of adapting an education program to be suited for patients?
- What are some key aspects that you would like to see included in a patient-centred Hospice education program?
- What content do you think is not relevant for a patient-centred program?
- How do you think we can meet different cultural needs for patients?
- How do you think education programmes can be developed to be most effective for patients?
- What are some challenges that you think patients might face in terms of engaging with the program? Both physical and emotional/mental?
- Family members and patients together or not?
- Should the program be education or social/support focused
- What is the difference between patients who engage with Hospice services and those who don't? How can those patients be brought into an education process? What are those patients' needs?
- What considerations should be taken in facilitating an education program for patients?
- Do you have any views on the length of the sessions and how many there should be, and the frequency of their occurrence?
- What do you think about running the program via Zoom, during Covid restrictions?
- Is there anything else you'd like to tell me about how you think the program could run?