Breaking Bad News about Cancer: The Experience of Patients, Patients' Family/Whānau Members and Healthcare Professionals

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ABSTRACT

Breaking bad news is a reality of medical practice in oncology, and can be a challenging task for those receiving and delivering the news. For patients and their family members, ‘bad news’ is understandably accompanied by strong emotions and ongoing implications for their lives as they adjust to the news. For healthcare professionals (HCPs), there are numerous variables to consider and balance when having these difficult conversations, as well as managing the personal impact.

The current study aims to explore the subjective experiences of patients, patients’ family/whānau members, and HCPs when bad news was delivered to patients about their cancer within the surgical departments of MidCentral District Health Board. The study is designed to allow multiple perspectives to be gathered and compared, and recommendations for practice to be made that align with the goals of those involved in the project’s inception, as well as attend to the underrepresentation of family members’ perspectives and New Zealand-based data in the literature.

To achieve this, the current study utilised a qualitative approach with the epistemological and methodological basis informed by interpretative phenomenological analysis. The study also included a consumer perspective with the involvement of the Otaki advisory group to guide how the study was conducted and provide feedback on the study outcomes. Data was collected through semi-structured interviews with 10 patients, 6 family/whānau members, 5 surgeons, and 6 nurses. Interviews were analysed in two ways: by participant group (i.e., patients, family members, and HCPs) and by ‘linked case’ (i.e., direct comparisons of the perspectives of all those involved in the same patient’s case of breaking bad news).

The findings are presented as a series of superordinate and subordinate themes. The group-based analysis highlighted that patients understood their bad news experiences through the lens of their health beliefs and expectations of care, the relational and support needs they, and others, had during and following the encounter, and the ongoing shifts in perspective and priorities they experienced. Family members identified the patient as the focus of care, but also acknowledged their need for support in order to cope. HCPs recognised that breaking bad news was challenging based on the variation between instances of breaking bad news and patients' needs, organisational constraints they had to work under, and the personal toll this task could take. The linked case-based analysis demonstrated that the receivers of bad news have a range of emotional and informational needs and that HCPs and family members fulfil important roles in accurately meeting patients' needs.

Four conclusions can be drawn from the study as a whole about the process of breaking bad news. Firstly, there is variability in the situations, delivery approaches and needs of those involved in breaking bad news, requiring a flexible and tailored approach. Secondly, establishing an interpersonal connection between the deliverer and receiver of bad news is a central part of the process. Thirdly, breaking bad news is a challenge for all and receiving support in order to cope, is paramount. Lastly, there is a shared responsibility across healthcare organisations, training providers, HCP teams, and individual HCPs to make this process go as well as possible for all those involved. The current research makes an important contribution to understanding that, without doubt, breaking bad news is a complex process for those delivering and receiving the news, and improvements in this area require careful consideration, prioritising and resourcing as part of delivering effective cancer care.

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During this thesis, we said goodbye to one of our family's central pillars: my very precious Grandpa Farm. For me, you are the original great storyteller and taught me the value of sharing experiences, establishing a strong oral tradition in our family. Your influence is woven into this thesis and I think about you often.

So, whether you contributed as a participant, advisor, supervisor, family member, partner, or friend, each and every one of you holds a special place in my heart. Thank you.

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[1] A requirement of the Doctor of Clinical Psychology internship programme. This case study provides a reflection on the transferability of research into clinical practice.

GLOSSARY

Throughout this thesis, Māori words are used to acknowledge the location of this thesis within New Zealand and its bicultural context. These terms are italicised within the text and a brief English translation provided in brackets immediately following the first time a word is used. However, a glossary is provided below to offer a more detailed explanation of the meaning of the words used in this thesis (Moorfield, 2011).

Aotearoa	North Island- now used as the Māori name for New Zealand
Hui	A gathering, meeting, or assembly
Iwi	Extended kinship group or tribe, often from a common ancestor
Kai	Food or meal
Karakia	Prayer, grace, or blessing
Koha	An offering or contribution
Kōrero	To speak or talk
Māori	Indigenous person of Aotearoa/New Zealand
Marae	Open area in front of the *wharenui* (meeting house) for formal greetings and discussions, and can include the complex of buildings around the marae
Mihi whakatau	Official welcome speech to acknowledge those present at a gathering
Pākehā	New Zealander of European descent
Te Tiriti o Waitangi	The Treaty of Waitangi
Whakawhanaungatanga	Process of establishing relationships or relating well to others
Whānau	Extended family- in the modern context, can include friends without kinship ties

CHAPTER ONE: THESIS OVERVIEW

Thesis Topic Development

In October 2014, a *hui* (meeting) was held at Raukawa Marae in Otaki, called "Whānau Lives Touched by Cancer" (Ngā whānau i pāngia e te mate pukupuku). This hui was attended by patients, their family members/*whānau* (family), and healthcare professionals (HCPs) from the surrounding region. The purpose of the hui was to hear *Māori* (indigenous person of New Zealand) and non-Māori people's experiences of cancer and palliative care services that were in operation. A main theme that emerged was the challenges inherent in the process of breaking bad news within the context of cancer and palliative care. In particular, it was identified that family members/whānau play a significant role throughout the breaking bad news process and that this has been under-recognised.

Present at the hui were members of the then established Cancer District Group (CDG) from MidCentral District Health Board (MDHB), whose focus was to work towards improving the way cancer services are delivered at a local and regional level. This group expressed an interest to Massey University in a study being conducted looking at the way bad news is delivered to patients with cancer within the MDHB; and more specifically, the processes that are followed within the surgical departments at Palmerston North Hospital.

From a more personal perspective, I have been brought up in a family that has a strong interest in the health and wellbeing of people and working towards delivering healthcare services in the best way possible. Like myself, my father and siblings all work in healthcare and are dedicated to not only providing their clinical skills, but delivering them in such a way that helps to enhance the overall wellbeing of the people they interact with. Conversations about bettering the experience of people in the healthcare system are dinner table conversations in my family. As well as this, narratives and stories have long been the way my extended family connects presently and, more importantly, to the past. We tell stories and re-tell stories to keep our history alive and stay connected, despite living on opposite sides of the world. Both these threads came together in this thesis: a belief in the power of lived experiences through sharing stories and a desire to optimise people's experiences in the healthcare system. My personal background married perfectly with the ideas that came from those who attended the 2014 Otaki hui and the CDG to form what this thesis has become. Throughout the research process, these groups remained involved in shaping how it was conducted.

Over the course of the research, the project evolved numerous times to arrive at the form presented in this thesis. Initially, the study was proposed to include recordings of consultations in which bad news was delivered, and then follow-up interviews with all parties involved. However, following consultation with senior hospital staff, it was decided that this would not be feasible from a logistical point of view, as well as being ethically contentious given the sensitivity of the content and vulnerability of the individuals at that time. The study design was altered to comprise retrospective accounts of receiving bad news gathered through semi-structured interviews.

Feedback on the outcome of the study and recommendations was important for the real-world application of this research. Research participants, those part of the project's beginnings, and other interested parties were given the opportunity to provide feedback during presentations of the findings, as well as when receiving the summary of the study findings. This feedback was not formally gathered or analysed and is thus not presented in the current thesis.

Study Aim and Objectives

The current study aimed to explore the subjective experiences of New Zealand patients (Māori and non-Māori), patients' family/whānau members, and HCPs (surgeons and nurses) when bad news was given to patients regarding a cancer diagnosis while accessing surgical services at Palmerston North Hospital. In addressing this aim, the current study had three objectives:

1. Explore patients' and their family/whānau members' experiences of receiving, and HCPs' experiences of delivering, bad news about cancer within MDHB surgical departments.
2. Directly compare the various perspectives of those involved in delivering and receiving bad news within a single patient's case.

3. Make practical recommendations from the findings for the improvement of delivering bad news within the MDHB surgical departments.

Thesis Context

This thesis was conducted in *Aotearoa* (New Zealand), which has a small population of 4.5 million, but with a significant geographical spread. New Zealand covers an approximate area of 270,000 square kilometres across the North and South Islands, comparable to the size of Japan or the United Kingdom (Cumming et al., 2014; Statistics New Zealand, 2015). New Zealand has a relatively recent human history, with Māori understood to have come to New Zealand in the late 13th Century from their ancestral homeland of Hawaiki (Walter & Reilly, 2018). *Pākehā* (Europeans) visited and began settling in New Zealand from the 17th Century.

New Zealand is considered to be a bicultural nation based on *Te Tiriti o Waitangi* (The Treaty of Waitangi) that was signed in 1840, which outlined the partnership between Māori and the British Crown (i.e., non-Māori; Orange, 2004). However, misunderstandings arose from differences in the English and Māori versions of the Treaty and the intention of mutual benefits for both people was not upheld, resulting in conflict and widespread possession of Māori resources by the British (Orange, 2004). Colonisation had devastating impacts on Māori land, health and traditional cultural practices, the effects of which can still be seen today (Durie, 2001). Based on the 2013 census, the New Zealand population consists predominantly of those who identify as New Zealand European (74.6%), along with Māori (15.6%), Asian (12.2%) and Pacific Island (7.8%) populations (Statistics New Zealand, 2015).

The healthcare system within New Zealand provides free inpatient and outpatient public hospital services, community support services and subsidised prescriptions. This is predominantly funded through public taxes (Cumming et al., 2014). Policies developed by the Ministry of Health guide a network of organisations that constitute the healthcare system. The day-to-day planning and funding of health services are the responsibility of twenty District Health Boards (DHBs) established nationwide that respond to the specific health needs of those in the geographical area they serve (Ministry of Health, 2017).

Cancer is responsible for 28.9% of deaths in New Zealand, making it the nation's leading cause of death (Ministry of Health, 2017). Cancer mortality rates for Māori are more than 1.5 times that of non-Māori, identifying Māori as a particularly important group to attend to in cancer care. This on-going major health issue is a national priority and in response to this, faster cancer treatment has become a national health target (Ministry of Health, 2017). The New Zealand Cancer Control Strategy Action Plan established four regional cancer networks to enhance collaboration in the implementation of cancer care. MDHB, the DHB of focus in this study, falls within the Central Cancer Network (Ministry of Health, 2017).

MDHB covers a catchment area that stretches from the West to the East coast of the lower central North Island. It includes the Horowhenua district, Manawatu district, Palmerston North city, Tararua district, and the Otaki ward of the Kapiti Coast district. MDHB services a population of 174,340 people, with approximately 20% identifying as Māori and 18% being 65-years or older (MidCentral District Health Board, 2014). There is a Regional Cancer Treatment Service available in Palmerston North that services those living in the surrounding regions. This means that many people have to travel a significant distance to this main centre to receive cancer treatment. In addition to hospital-based care, cancer support services for adults living in the MDHB district include the Cancer Society, *iwi* (tribe)-based Māori cancer coordinators, foundations for specific cancers (e.g., Leukaemia and Blood Cancer New Zealand, Prostate Cancer Foundation of New Zealand), and the Massey University Cancer Psychology Service.

The rationale for conducting this research within one DHB was that there is regional variation in services for patients with cancer and their family/whānau based on how the DHB decides to allocate their funding. Having all participants cared for, or employed, by MDHB enabled the findings and recommendations that arose from the research to be directly relevant to MDHB and those whom it serves.

Thesis Style

This thesis is written in the style of 'thesis with publication'. It is comprised of two manuscripts written for publication in academic journals and interlinking chapters that weave the thesis into a coherent narrative. The manuscripts have been written in the style of the academic journal in which they have been published or submitted, including conforming to the journal's required content and word limits. However, to maintain consistency throughout the thesis, referencing and formatting have been altered to fit the overall style of the thesis, and a single reference list is provided at the end. For ease of reading, tables, figures, and appendices have been listed consecutively throughout the entire thesis, which may differ from numbering that appears in published versions of the manuscripts. While effort has been made to keep repetition to a minimum, some repetition of information was unavoidable due to the manuscripts needing to be understood in isolation from the full thesis.

Overview of Thesis Chapters

This thesis is presented in six chapters, with Chapters One, Two and Three establishing the background to the thesis and Chapters Four, Five and Six presenting the current research and findings. Following this overview chapter, Chapter Two presents an introduction to the topic of breaking bad news to orient the reader to the research area. Chapter Three provides a review of the qualitative literature on the experiences of those involved in the process of breaking bad news about cancer and will be presented in three parts. *Part One* is a meta-synthesis of qualitative studies of the experiences of patients and their family members when bad news is delivered to patients about cancer and is written as the first manuscript in this thesis. *Part Two* presents the literature on HCPs' experiences of delivering bad news and is written in chapter format given the recently published meta-synthesis on this topic (Bousquet et al., 2015). *Part Three* provides a critique of the literature reviewed in *Part One* and *Two*, outlining suggestions for future research.

Turning to the current study, Chapter Four outlines the study rationale, aims, methodology and method. Chapter Five will detail the research findings, with a discussion presented alongside. This will be written in two parts representing two different ways the data were analysed: by group and by 'linked case' (see Terminology). *Part One* describes the experiences of patients, patients' family members, and HCPs, written in chapter format (addressing objective 1). *Part Two* presents a direct comparison of the perspectives of those involved in a series of single-patient cases of breaking bad news and will form the second manuscript for publication in this thesis (addressing objective 2). Chapter Six offers a series of conclusions that can be drawn across the findings as a whole and recommendations for improvements to the breaking bad news process within MDHB (addressing objective 3). Finally, key considerations for the study outcomes, future research directions, and the contribution the study has made to the literature, will conclude Chapter Six and the thesis.

Terminology

To align with the existing literature, which largely comes from a medical context, the term ‘patient’ is used in this thesis to refer to an individual who has been diagnosed with cancer. ‘Family/whānau member’ refers to anyone who is close to the patient and does not necessarily need to be a biological relative. The Māori word ‘whānau’ is used to acknowledge the broad definition of ‘family’ adopted within Māori culture, an important consideration given this thesis is located in New Zealand’s bicultural context and includes Māori participants (see Glossary). ‘Healthcare professional’ (HCP) refers to any trained professional working within a healthcare setting that is involved in the delivery of bad news about cancer. A ‘linked case’ refers to a collection of interviews where the perspectives of patients, their family/whānau members, and HCPs are gathered concerning a single patient’s case of breaking bad news (see Chapter Four for more detail).

CHAPTER TWO: INTRODUCTION

Breaking Bad News

Breaking bad news to patients and their families is an unavoidable reality that healthcare professionals (HCPs) face on a regular basis. It is a complex communication task that has many facets and implications for the receivers, as well as the deliverers, of the news. This chapter will introduce the area of breaking bad news by defining what is meant by 'bad news', describing what makes this a significant process for all those involved, providing a brief history of this type of communication, and outlining key considerations when bad news is delivered. Models that are designed to guide HCPs to deliver bad news well will then be discussed, along with training programmes that teach HCPs this crucial communication skill.

What is 'Bad News'?

What is considered 'bad news' in the health context, and the impact of that news, can vary, as this understanding involves a degree of subjectivity on the part of the receiver (Fallowfield & Jenkins, 2004). The 'badness' of the news lies in the space between what the patient's expectations are and the reality of their medical condition (Buckman, 1992). As such, no strict parameters can be put on what is and is not 'bad news' for an individual. The personal impact is informed by an individual's current life situation, previous life and illness experiences, their personality, cultural and social background, spiritual beliefs, social support and emotional resilience (Fallowfield & Jenkins, 2004). A further nuance is that bad news may not only evoke negative feelings. An individual may experience a combination of relief to receive an explanation for their symptoms, as well as sadness at the poor prognosis (Alexander & Klein, 2000).

To account for this, definitions of bad news offered in the literature are appropriately broad to allow for such variation. For example, Ptacek and Eberhardt (1996) defined bad news as information that "…results in a cognitive, behavioural, or emotional deficit in the person receiving the news that persists for some time after the news is received" (p. 496). While this definition was proposed many years ago, it remains cited in recent literature (e.g., Abazari, Taleghani, Hematti, & Ehsani, 2016).

Traditionally, imparting bad news has been conceptualised from the healthcare providers' standpoint as the one-off event when information is transmitted by a doctor to the patient (Warnock, 2014). However, this simplistic understanding does not acknowledge the context surrounding the delivery, which in the oncology setting can include real or feared suffering and threat to life (Stiefel & Bourquin, 2016). The patient's perspective of how it is to receive bad news is also not accounted for.

Research has shown that patients view bad news as a process over time rather than a single communicative event, with significant moments for the patient before, during and after the bad news is shared (Tobin & Begley, 2008). Exemplifying this broader conceptualisation, Salander (2002) found that when patients spoke about receiving bad news, they described their overall experience of being 'diseased by cancer'. Viewing bad news as a process over time also acknowledges the important contribution that other members of the multidisciplinary team, such as nurses, social workers, psychologists and chaplaincy staff, make to the process (Kirby, 1998; Warnock, 2014).

The Significance of the Bad News Encounter

Patients and family members. Receiving the news of a diagnosis of cancer is, understandably, a highly emotional experience for patients. Possible emotional reactions to this news are varied and can include shock, disbelief, denial, fear, anxiety, anger, sadness, relief, and acceptance (Fallowfield & Jenkins, 2004). Patients may also be inclined towards asking "why me?" and searching for reasons for their ill-health (Buckman, 1992). Ptacek and Eberhardt (1996) proposed a model of stress associated with the delivery of bad news over time, contrasting the experience of the patient and the physician. It suggested that patient stress levels peak after the news has been given, highlighting the period post news transmission as particularly important for the patient to receive support. In theorising the various responses patients have to bad news, Sweeny and Shepperd (2007) suggested that most emotional responses helped move a patient towards maximising their quality of life, except for those engaging in denial or dismissal of their medical reality. However, it may be argued that denial is a necessary stage in coping with, and processing, bad news, as suggested in the stages of grief model (Kübler-Ross, 1973).

The quality of the HCPs' delivery of bad news has been shown to impact on patient satisfaction with the care they receive (Brown, Parker, Furber, & Thomas, 2011) and their long-term psychological adjustment to the news (Roberts, Cox, Reintgen, Baile, & Gibertini, 1994). Bad news delivered poorly has been reported to result in increased patient anxiety (Zheng, 2011), while an effective delivery has been suggested to reduce patient distress and increase their satisfaction with their medical care (Schofield et al., 2003).

However, a review by Paul, Clinton-McHarg, Sanson-Fisher, Douglas, and Webb (2009) found that there are limited rigorous intervention studies aimed at improving the psychological outcomes for patients following receiving bad news. They concluded that at present, ways of approaching delivering bad news are based on the opinion of experts, rather than research evidence, and that many studies assume that improving HCPs' skills will result in benefits for the patient (Paul et al., 2009).

The process of receiving bad news can also have significant implications for patients' family members, as they are often present when bad news is delivered and are the primary source of support for the patient (e.g., Abazari et al., 2016). While the patient is typically the main focus during the bad news delivery, it must be recognised that the family are also receiving bad news and may be as affected as the patient. Buckman (1992) reported that family members have similar emotional reactions as the patient to bad news, but often carry the additional burden of wanting to protect the patient from distressing information.

Healthcare professionals. Delivering bad news to a patient has been proposed as one of the most challenging parts of a HCP's job and the greatest test of their communicative competence (Greening, 2008; Martis & Westhues, 2013). HCPs report delivering bad news as stressful, even when exposed to this in a simulated environment (Meunier et al., 2013; Shaw, Brown, Heinrich, & Dunn, 2013). Doctors are frequently exposed to this stress due to the numerous times they are required to deliver bad news, with New Zealand data suggesting that some doctors do so 10-15 times per week (Deighton, 2013).

Ptacek and Eberhardt's (1996) model of stress over the course of breaking bad news shows that HCPs' stress levels rise in anticipation of having to deliver bad news. The literature suggests that many factors are likely to inform this. Firstly, modern advancements in medical technology have created a perception that death is a failure, leading many HCPs to feel guilty and ineffective when having to report undesirable medical results (Brixey, 2004; Buckman, 1992). Secondly, HCPs may fear the intensity of patients' and family members' emotional reactions, particularly as the phenomenon of 'shooting the messenger' may occur (Alexander & Klein, 2000). Thirdly, HCPs can be concerned about their ability to manage their own emotions and that this might compromise their professionalism and clinical judgment (Buckman, 1992; Chittem & Butow, 2015). Lastly, HCPs, especially those early on in their careers, can feel ill-prepared through inadequate training to manage the complexity of this communicative task and its emotional implications (Alexander & Klein, 2000). Warnock, Buchanan, and Mary (2017) developed a framework to conceptualise the difficulties HCPs faced when breaking bad news, suggesting that the process was complicated by situational (e.g., unexpected news, transitions in care, and ethical dilemmas), organisational (e.g., insufficient time, staff and resources), individual (e.g., knowledge, confidence, and emotional consequences), and patient/relative variables (e.g., emotional reactions and family dynamics).

If bad news is delivered well, however, it is not all bad news for HCPs and their patients. When HCPs break bad news effectively, Buckman (1992) suggested that this might enhance a HCP's satisfaction with their career and protect them from burnout. A study from India reported that physicians perceived delivering bad news as helping them improve their levels of empathy and the overall care they provided to patients and families (Martis & Westhues, 2013). Studies have also suggested that successfully navigating the bad news process can enhance the patient-HCP relationship by increasing patient trust, rapport and positive perceptions of the care they receive, which can be rewarding for both the patient and the HCP (Greening, 2008; Sherman, Moss, & Redman, 2013).

History of Bad News Communication

Historically, bad news about illness was withheld from patients for fear that disclosing the truth would destroy their hope and cause further deterioration in their health (Buckman, 1992). Hippocrates gave this warning by stating that a patient may ‘take a turn for the worse’ if told the truth about their medical condition (Schoefl, 2008). The potentially negative impact of a physician’s words on the physical health of a patient was outlined in the first American Code of Ethics, which called for doctors to avoid anything that would discourage the patient or dampen their spirits (Katz, 1984). As such, the stance of the medical profession at this time exemplified paternalism.

An early advocate for truth-telling was French physician, Samuel de Sorbiére who, in 1672, considered telling his patients the truth about their illnesses. However, he feared this approach would compromise his medical practice and doubted that the medical profession would welcome this change (Buckman, 1992). A landmark study conducted in 1961 in America found that 90 percent of physicians would routinely withhold disclosing a cancer diagnosis to a patient (Oken, 1961). When the study was repeated almost 20 years later, a marked shift in attitude was observed, with 90 percent of physicians reporting that they would break the news of cancer to a patient (Novack et al., 1979). The trend towards full disclosure continues in modern society, reflecting a paradigm shift from paternalism to promoting patient autonomy (Schoefl, 2008).

Key Considerations when Breaking Bad News

Disclosure versus non-disclosure. In Western countries, a patient knowing the truth about their health and being fully informed is viewed as their right (Windsor et al., 2008) and is reflected in Western guidelines on how to break bad news (e.g., Baile et al., 2000). However, there are still parts of the world where there is non- or partial disclosure of health-related bad news. Subscribing to a non-maleficence model, many HCPs in Eastern European, Italian and African communities withhold the truth from patients due to the belief that this will expose them to unnecessary psychological and physical harm, preferring to disclose the news to their families (Ferraz Gonçalves & Castro, 2001; Windsor et al., 2008).

Studies from Western and non-Western cultures suggest that while the majority of patients want to be informed of their diagnosis (e.g., (Aminiahidashti, Jaber Mousavi, & Mehdi Darzi, 2016; Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005), some patients and family members still prefer non-disclosure (e.g., Beqiri, Toci, Sallaku, Qirjako, & Burazeri, 2012). Some studies have indicated that family members have a greater desire for bad news to not be disclosed to the patient, than the patient themselves. In Peru, Monge and Sotomayor (2004) found that while 91 percent of patients wanted to be told their diagnosis, only 57 percent of their relatives agreed with this disclosure.

Navigating the decision of whether to disclose bad news to a patient requires the consideration of the potential ethical dilemmas and consequences that may arise. If HCPs respect a family's request for non-disclosure, they must balance the ethical dilemma of administering treatment to the patient without them being able to participate in the decision-making process (Chittem & Butow, 2015). Additionally, when the patient inevitably finds out about the nature of their condition as they deteriorate, this can compromise trust in their HCP (Silbert, 2011). The consequences of non-disclosure to patients have been suggested to include compromising patient-family communication, increasing uncertainty about the illness trajectory, creating unrealistic expectations for recovery, and preventing the patient getting their affairs in order (Alexander & Klein, 2000; Chittem & Butow, 2015). These shortcomings are, however, likely to be Western-centric where the cultural norm is strongly in favour of upholding patient autonomy.

Approaches to care. The general consensus amongst Western HCPs is that taking a patient-centred approach to the communication of bad news is best practice, which means letting the patient's needs direct the way news is delivered (Ptacek & Eberhardt, 1996; Ptacek, Fries, Eberhardt, & Ptacek, 1999). There is evidence to suggest that the majority of patients also prefer a patient-centred style of communication (Swenson, Buell, Zettler, & White, 2004). Mast, Kindlimann, and Langewitz (2005) conducted a study comparing patient-, disease-, and emotion-centred approaches to communication, using video examples. The findings supported a patient-centred approach, as these participants were the most satisfied with consultations that followed this approach. This was in contrast to emotion-centred communication that involved an excess of sympathy and empathy, which was perceived as the least appropriate style of information exchange and resulting in the least amount of hope (Mast et al., 2005). A patient-centred approach has formed the basis for recent training for HCPs in breaking bad news (e.g., Bishop et al., 2016).

In Asian cultures, however, where family is of central importance, a family-centred approach to medical care is widely practised (Naseem, 2018). This means that family members are fully informed of a patient's health status and take a lead role in decision-making, as what happens to the patient impacts the functioning of the whole family unit. In a review of patient preferences when breaking bad news, Fujimori and Uchitomi (2009) found that patients from family-centric cultures, such as found in Japan, desired family members to be present when bad news was delivered, more so than those from Western cultures. A family-centred approach was also favoured in medical codes of ethics from Islamic countries when it came to disclosing bad news about terminal illness (Abdulhameed, Hammami, & Mohamed, 2011).

Verbal and non-verbal communication. The accurate verbal communication of information is crucial when delivering bad news so patients and their families can make informed decisions. When working with a diverse patient population, HCPs may experience language barriers that require the presence of an interpreter (Naseem, 2018). Commonly, family or friends of the patient will provide this service, which has the benefit of them knowing the patient and providing emotional support (Gerrish, Chau, Sobowale, & Elizabeth, 2004).

However, HCPs have concerns that family may, intentionally or unintentionally, misrepresent what the HCP has said, to protect the patient from the distress of knowing the reality of their illness (Clayton, Butow, & Tattersall, 2005a; Friedrichsen & Milberg, 2006). Consideration has also been given to the potential emotional impact on family members of being the bearer of bad news (Elit et al., 2015; Prentice, Nelson, Baillie, Osborn, & Noble, 2014). As such, the use of a professional interpreter is often seen as ideal, but can create discomfort for the patient when sharing personal details, especially if the interpreter is from their own community (Phelan & Parkman, 1995).

Even if HCPs and patients share the same spoken language, variation has been found in patients' preferences for the types of words HCPs use. In qualitative studies based in Iran, there was a strong preference for avoiding the word 'cancer' in favour of less negatively charged words such as 'tumour', because cancer is considered a taboo subject (Abazari et al., 2016; Zamanzadeh et al., 2013). This is in contrast to guidelines in Western cultures, such as Australia (Clayton, Hancock, Butow, Tattersall, & Currow, 2007) and Canada (Canadian Patient Safety Institute, 2011), which emphasise using clear, non-ambiguous terminology.

During the process of delivering bad news, non-verbal communication is a significant part of the exchange (Naseem, 2018; Radziewicz & Baile, 2001). Interpretation of behaviours such as eye contact, smiling, nodding, leaning forward and physical touch can vary across cultures, making it important for HCPs to obtain cultural competency in working with diverse populations. For example, a Muslim female will avert eye contact with a male HCP as an act of modesty, rather than signalling a lack of trust (Naseem, 2018). In Japanese culture, there is a norm of formality as opposed to familiarity when engaging with a HCP, with Japanese patients preferring a physician to not hold their hand or touch their arm when delivering bad news (Fujimori et al., 2007).

Models to Guide Breaking Bad News

Numerous published models have been developed across different cultural settings to support HCPs in the effective delivery of bad news to patients (see Table 1). Abdul Hafidz & Zainudin (2016) provided a summary of the common themes across these models, which included being prepared before the session (e.g., anticipating difficult questions), preparing the setting (e.g., a private room that can accommodate family and friends), exploring what the patient knows and expects (e.g., what information is needed and addressing misconceptions), clear and direct communication (e.g., avoid medical jargon and vague terminology), addressing emotional reactions (e.g., expressing empathy) and summarising the main points of the session.

There is, however, variation across the models in the variables considered important for effective bad news delivery. One of these is in regards to the recognition and emphasis put on the role of the family. The SPIKES model (Baile et al., 2000) does not explicitly integrate

Table 1

Models for Breaking Bad News

Author	Country	Context	Description
Baile et al. (2000**)**	USA	Oncology	SPIKES: Setting (location, allow time), Perception (patient's view of condition), Invitation (to deliver news), Knowledge (deliver news, provide information), Emotions (empathy), and Strategy and summary (clear plan)
Rabow & McPhee (1999)	USA	NS	ABCDE: Advanced preparation, Build a therapeutic relationship, Communicate well, Deal with patient and family reactions, and Encourage and validate emotions
Narayanan, Bista, & Koshy (2010)	India	Oncology	BREAKS: Background (knowledge of patient's problem), Rapport, Explore (what patient knows), Announce (warning shot then news), Kindling (space for emotions), and Summarise (session and treatment plan)
Villagran et al. (2010)	USA	NS	COMFORT (communication competencies, not a linear guide): Communication (verbal and non-verbal skills), Orientation (to diagnosis and prognosis), Mindfulness (HCP is present in the moment), Family (included), Ongoing (non-abandonment), Reiterate (repeat message), and Team (consistent messages)
Tang et al. (2014)	Japan	Oncology	SHARE: Supportive environment, How to deliver bad news, Additional information, Reassurance, and Emotional support.
Back, Arnold, Baile, & Tulsky (2005)	USA	Oncology	NURSE (addressing emotional distress): Naming the emotion, Understanding concerns, Respecting the patient, Supporting patient's ability to cope, Exploring emotions and questions
Garg, Buckman, & Kason (1997)	Canada	NS	Six-point protocol: 1. Getting the setting right (private) 2. Finding out what the patient already knows 3. Finding out what the patient wants to know 4. Giving information (deliver news and educate) 5. Responding to patient's reactions (empathy) 6. Closing (summarise and patient questions)
Girgis & Sanson-Fisher (1998)	Australia	Oncology	12 essential steps: 1. Give bad news in a quiet place 2. Allow enough uninterrupted time 3. Assess understanding and emotional status 4. Provide information simply and honestly 5. Encourage expression of emotions 6. Respond with empathy 7. Broad timeframe for prognosis 8. Avoid conveying no hope 9. Arrange review 10. Discuss treatment 11. Support services 12. Document
Salem & Salem (2013)	Muslim countries	Oncology	IGAD: Interview (patient consent to have family present), Gather (information on the desired level of disclosure), Assess (expectations for religion and family), Achieve (rapport), Decide (the appropriate level of disclosure), Disclosure (deliver news), Discuss (summary and support)
Pereira, Calônego, Lemonica, & Barros (2017)	Brazil	NS	PATIENTE (in Portuguese): Prepare (HCP informed), Assess patient's knowledge and how much they want to know, invite patient to the Truth (forewarning), Inform, Emotions, do not abandon the patient, outline the strategy (care and treatment)
Laidsaar-Powell, Butow, Boyle, & Juraskova (2018)	Australia	Oncology	TRIO Guidelines (for involving family): 1. Facilitate collaborative family involvement 2. Welcome family attendance 3. Build rapport and show respect to family 4. Careful communication of information 5. Be observant of the patient and family relationship 6. Meet family caregiver's emotional and informational needs.
Nardi & Keefe-Cooperman (2006)	USA	Emergency Mental Health	PEWTER: Prepare (educationally, psychologically, physically and spiritually), Evaluate (what the listener knows), Warn (forewarning), Tell (delivering the news and assess understanding), Emotional response (sensitivity and support), and Regroup (plan next course of action).

Note. USA= United States of America; NS= Not specified; HCP= Healthcare professional the important role family have in supporting the patient and planning their care, or the emotional impact the news will have on them. By contrast, the COMFORT model includes considering family as one of the core communication principles (Villagran, Goldsmith, Wittenberg-Lyles, & Baldwin, 2010), and the ABCDE model acknowledges that the emotions of both the patient and the family need to be addressed during the consultation (Rabow & McPhee, 1999). Models from non-Western settings, such as IGAD developed for Muslim countries, recognise the importance of religion and establishing the appropriate level of disclosure (Salem & Salem, 2013), which is not considered in Western models.

The SPIKES model is one of the most widely utilised and evaluated models in training and practice guidelines for breaking bad news (Stiefel, de Vries, & Bourquin, 2018; see Table 1 for model description). Within New Zealand, the MidCentral District Health Board (2010) produced guidelines for breaking bad news based on the SPIKES model. The SPIKES model was originally designed for use within an oncology setting (Baile et al., 2000) and follows a similar structure to the Calgary-Cambridge model that is commonly used to guide clinical interviewing (Dean & Willis, 2016). Medical professionals and students who have been taught the SPIKES protocol report greater confidence in areas such as detecting sadness and being empathetic when communicating unfavourable news to patients (Baer et al., 2008; Baile et al., 2000).

Studies have indicated support for the effectiveness of the SPIKES model internationally, including in the United Kingdom (e.g., Fallowfield, Jenkins, Farewell, & Solis-Trapala, 2003), United States of America (e.g., Baile et al., 1999), Japan (e.g., Fujimori et al., 2003), China (e.g., (Wuensch et al., 2013), and Germany (e.g., Goelz et al., 2011). However, this has not been consistently found, with Seifart et al. (2014) reporting less than half of German patients being satisfied with how they had been told bad news when the delivery was based on the SPIKES protocol. The authors suggested that the SPIKES model may not meet the needs of all patients, due to the diverse preferences individuals have for how they want bad news to be broken (Seifart et al., 2014).

There are several limitations to the models designed to guide HCPs in the breaking of bad news. Firstly, while these models are considered as having the patient's interests at heart, there is evidence that patients' preferences are not the central focus when guidelines are developed. Recommendations in many of the protocols are driven by expert opinion, rather than patient-based empirical evidence (Girgis, Sanson-Fisher, & Schofield, 1999; Seifart et al., 2014). Secondly, models have been criticised for being too focused on the transmission of information, detracting from the importance of the HCP forming a relationship with the patient (Salander, 2002). Thirdly, the SPIKES model was developed by doctors for doctors and does not recognise the crucial role that the wider team, such as nurses, have during this process (Dean & Willis, 2016). Lastly, outcome measures of HCPs utilising models to guide bad news delivery tend to focus on HCPs' confidence levels, rather than the patient's experience (Fallowfield & Jenkins, 2004). While it is inconclusive as to whether models are helpful to patient outcomes, Dean and Willis (2016) suggested that there is evidence that HCPs value some guidance as to how to approach this complex task.

Training in Breaking Bad News

Given the gravity of the task of breaking bad news and the potentially negative impact of delivering bad news poorly, providing training to health professionals is essential. Training HCPs to deliver bad news well has been shown to increase their effectiveness and confidence with this complex task and reduce the psychological distress of patients, their families and carers (Abdul Hafidz & Zainuin, 2016; Moore, Mercado, Artigues, & Lawrie, 2013). Traditionally, communication skills have, however, been less emphasised than clinical or technical proficiency in medical training programmes (Abdul Hafidz & Zainudin, 2016; Monden, Gentry, & Cox, 2016), with newly qualified doctors often left to rely on informal learning through experience and observation (Arnold & Koczwara, 2006; Monden et al., 2016). Studies have reported that HCPs are aware of their deficit in formal training and desire further skill development. For example, Monden et al. (2016) found that 85 percent of surgeons at a medical centre in the US felt they needed additional training in breaking bad news.

The recognition that doctors require, and desire, formal training in breaking bad news has led to numerous training programmes being developed for HCPs at different levels of training (e.g., Brouwers, Bor, Laan, van Weel, & van Weel-Baumgarten, 2018; de Almeida & Agnoletti, 2015; Gorniewicz et al., 2016; Skye, Wagenschutz, Steiger, & Kumagai, 2014). In a review of training programmes for surgical residents, Lamba, Tyrie, Bryczkowski, and Nagurka (2016) found that a combination of modalities was commonly used, including didactic sessions, video vignettes, discussion forums and tests of skills using standardised patients. Recently, training programmes have also made use of virtual reality technology (Andrade, Bagri, Zaw, Roos, & Ruiz, 2010). In a meta-analysis of randomised controlled trials of the implementation of communication training programmes, Moore et al. (2013) found that HCPs who underwent communication skills training were more likely to ask open questions and show greater empathy. However, the authors concluded that it remained unknown what type, duration or intensity of training was most effective (Moore et al., 2013).

The establishment of best practice guidelines and recommendations for communication training programmes have been a focus of researchers in this field (Stiefel et al., 2018). Lamba et al. (2016) proposed using didactic sessions, followed by practice using simulation and role-play, and Objective Structured Clinical Examinations for evaluation and feedback. Kurer and Zekrim (2008) suggested training occurred over time, starting in medical school with theory and role-plays, followed by observing senior staff in the early stages of practice and asking questions, and finally being supervised while delivering bad news, and receiving feedback.

Recently, there has been a suggestion to move away from a focus on skill attainment to looking at individual clinician's resources and needs when delivering bad news in an oncology setting (Stiefel & Bourquin, 2016). To do this, reflexive practice has been promoted and taught to medical students to develop skills in reviewing their own practice (Berney & Bourquin, 2019; Stiefel & Bourquin, 2016).

Summary

Breaking bad news is a complex task that requires a broad definition to capture the diverse circumstances that can be considered 'bad news' and the variation in the way individuals react. For patients and their family members, the challenge of hearing bad news is based on the reality that their own, or loved one’s, health and future are under threat. While there is no easy way to hear bad news, the literature suggests that the quality of HCPs’ delivery has a role to play in how satisfied patients are with their care and how well they adjust to the news. What is considered optimal care has evolved over time to align with changes in medical ethics from prioritising paternalism to promoting patient autonomy.

However, there continues to be international variation in how breaking bad news is managed, often reflective of Western versus non-Western cultural norms and values. As such, key consideration for HCPs when delivering bad news include whether or not full information is disclosed, if care is delivered in a patient- or family-centric fashion, managing language barriers and wording preferences, and variation in interpretations of non-verbal communication. The complexity of this task for HCPs is reflected in the numerous models that have been published to help guide them to effectively break bad news, as well as training programmes for HCPs to develop the necessary communication skills.

Overall, the process of breaking bad news is a significant event for patients and their family members, as well as for the HCPs delivering the news. A particular area that has attracted extensive research attention is the breaking of bad news about cancer and how all those involved experience this. The next chapter will consider this topic in more detail by reviewing the existing qualitative literature on breaking bad news in oncology.

CHAPTER THREE: REVIEW OF THE LITERATURE

The challenging and complex process of delivering and receiving bad news about cancer has been captured in qualitative literature, internationally. This chapter presents a review and critique of the existing literature, organised into three parts.

Part One concerns the experiences of adult patients and their family members when receiving bad news about cancer. While not an explicit aim of the thesis, it was evident from reading the existing literature that there was a need for a synthesis of this corpus of qualitative literature. Therefore, *Part One* of this chapter takes the form of a meta-synthesis and is the first manuscript in this thesis. This manuscript has been published in Psycho-Oncology and is presented to the requirements of the journal, except for the referencing style and formatting that remains consistent with the overall thesis (see Appendix A for the statement of candidate contribution to the publication). The full reference for this published manuscript is:

Matthews, T., Baken, D., Ross, K., Ogilvie, E., & Kent, L. (2019). The experience of patients and their family members when receiving bad news about cancer: A qualitative meta-synthesis. *Psycho-Oncology, 28*(12), 2286-2294. doi: 10.1002/pon.5241

Part Two offers a review of qualitative research on the experiences of healthcare professionals when delivering bad news to adult patients about cancer. This will be presented in chapter format, acknowledging the recent publication of a meta-synthesis on this topic (Bousquet et al., 2015).

Part Three will offer a critique of the existing literature that informed the development of the study presented in this thesis.

CHAPTER THREE: REVIEW OF THE LITERATURE

Part One:

The Experience of Patients and their Family Members when Receiving Bad News about Cancer: A Qualitative Meta-synthesis

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Abstract

This qualitative meta-synthesis explored the subjective experiences of patients and their family members when receiving bad news about cancer, with a focus on what was important to them during this process and making future recommendations. A search of five electronic databases yielded 587 different records that resulted in 88 articles assessed against the inclusion/exclusion criteria. With the supplement of 4 additional records, 29 articles were analysed using thematic synthesis. A quality appraisal checklist was used to provide further information about the included articles. Patients and family members experienced receiving bad news as a process that involved three phases, labelled: ‘preparation’, ‘delivery’, and ‘adjusting and coping’. The ‘preparation’ phase had four themes: the setting, developing a relationship, knowing the patient, and forewarning. Four themes were identified during the ‘delivery’ phase: emotional reactions, empathy not sympathy, active participation, and understanding. ‘Adjusting and coping’ comprised four themes: hope, holistic support, being a protector, and on-going relationships. Receiving bad news is a significant experience for patients and family members. They want bad news delivered in an appropriate setting, in a manner consistent with their personal preferences, and have their psychological needs attended to within the context of an established relationship. Healthcare professionals can be assisted to deliver bad news in the best way possible by additional training and their workplace institutions providing quiet, private rooms and sufficient time. Future research is needed to better understand family members’ experiences and needs.

Keywords: Bad news, cancer, family member, oncology, patient, qualitative meta-synthesis, truth-telling

Background

Receiving bad news about cancer, whether it takes the form of a diagnosis, prognosis, or change in treatment or care, is a significant and difficult moment for patients and their family members. It is, understandably, a highly emotional process that may include reactions such as shock, sadness, anger, disbelief or denial (Fallowfield & Jenkins, 2004). Within the healthcare literature, bad news has been defined as information that "…results in a cognitive, behavioural, or emotional deficit in the person receiving the news that persists for some time after the news is received" (Ptacek & Eberhardt, 1996, p. 496).

There is evidence that the quality of how bad news is delivered has an impact on those receiving the news, such as influencing psychosocial adjustment, coping, healthcare outcomes, satisfaction with care, level of uncertainty, and anxiety and depression (Hagerty et al., 2005; Mager & Andrykowski, 2002; Schofield et al., 2003; Seifart et al., 2014). Guidelines have emerged to assist healthcare professionals (HCPs) to do this inherently difficult task in the best way possible for the patient and their family members. One such model is the 6-step SPIKES strategy (Setting up the interview, assessing the patient's Perception, obtaining the patient's Invitation, giving Knowledge and information, addressing Emotions with empathetic responses, and Strategy and summary) that was designed specifically for application within a Western oncology setting (Baile et al., 2000) and is used widely in training and practice (Stiefel et al., 2018). However, there is evidence from a study conducted in Germany that the SPIKES model does not meet the needs of all patients (Seifart et al., 2014) , likely due to their diverse preferences for how bad news is delivered. Additionally, the SPIKES model does not overtly consider family issues, which may be particularly problematic in Eastern, and some indigenous (e.g., Māori), cultures where family involvement is important. In response to diversity cross-culturally, models for how to break bad news in specific settings have been developed, such as within Japanese culture (Tang et al., 2014) and Muslim countries (Salem & Salem, 2013).

Numerous quantitative studies have explored the preferences of those receiving bad news internationally, mostly utilising questionnaires (Chiu et al., 2006; Eng, Yaakup, Shah, Jaffar, & Omar, 2012; Fujimori, Akechi, & Uchitomi, 2016; Goncalves et al., 2005). Evidence from such studies suggests that across cultures the majority of patients want to be informed of their diagnosis (Aminiahidashti et al., 2016), would like the news delivered by a physician (Arbabi et al., 2014; Goncalves et al., 2005), and want the news to be given in a calm way in a private place (Alrukban et al., 2014; Aminiahidashti et al., 2016). However, such studies infrequently include family preferences and, due to being survey-based, may be limited in their ability to provide a nuanced perspective on this complex process for the receivers of bad news. As Pollock, Moghaddam, Cox, Wilson, and Howard (2011) suggested, qualitative findings in this area are important to contextualise such survey outcomes.

In response, studies utilising qualitative methodologies have explored the subjective experiences of patients and their families when told bad news about cancer (Chircop & Scerri, 2017; Friedrichsen, Strang, & Carlsson, 2001; Hoff, Tidefelt, Thaning, & Hermerén, 2007; Randall & Wearn, 2005). These studies are commonly conducted with small sample sizes and provide an in-depth view of the experiences of patients and their families within specific cancer types, healthcare contexts and countries. It is currently unknown if these qualitative findings are consistent with quantitative results, and if so, could provide further confidence in the findings.

Qualitative meta-synthesis is an approach that has previously been applied by Bousquet et al. (2015) to systematically review qualitative studies of the experiences of HCPs when delivering bad news to patients about cancer. This synthesis identified that HCPs have the challenging role of balancing numerous factors within the patient-HCP relationship, such as the patient’s wishes, the need to inform, sustaining hope, being cautious with language, and attending to their own, and patients’ emotions. HCPs also needed to adapt to external variables that impacted the interaction, such as the role of the family in the encounter, systemic and institutional demands (i.e. lack of time, privacy and communication within the healthcare team) and cultural variation in preferences and expectations (Bousquet et al., 2015).

To date, there is yet to be a synthesis of the diverse experiences of patients and their family members receiving bad news about cancer reported in the literature. The process of meta-synthesis was chosen for the current review as it is said to go beyond simply identifying common threads across articles and instead employs a thorough analysis with the potential of revealing new insights (Paterson, Thorne, Canam, & Jillings, 2001). Such insights may be beneficial for informing HCPs about how best to deliver bad news to patients and their family members. Therefore, the current paper presents a meta-synthesis of qualitative studies that aims to: (a) gain an understanding of the subjective experiences of patients and their family members when given bad news about cancer, with a focus on what was important to them during this process, and (b) offer practical recommendations of ways to improve the process of how bad news is delivered to patients and their families in the future. The review was conducted to align with the eMERGE guidelines for synthesising qualitative literature (France et al., 2019). For a description of the guideline criteria and the page number(s) in the review where each criterion was met, see Appendix B.

Methods

Article Selection

Extensive effort has been made to capture the relevant literature on the subjective experiences of patients and their family members when receiving bad news. The initial strategy for identifying relevant articles involved searching five databases (SCOPUS, Web of Science, CINAHL Complete, PsycINFO and PubMed) on 17th March 2017, using the keyword search ("bad news" OR "truth disclosure") AND (reaction* OR emotion* OR experienc*) AND (qualitative OR phenomenolog* OR ethnograph* OR "grounded theory" OR "case stud*" OR hermeneutic*) AND (cancer* OR neoplasm* OR oncolog*). The search captured all available records since each database's inception. The database search was repeated on 9th January 2019 to capture articles published since the initial search. A total of 587 articles (excluding duplicates) were independently screened by the primary author (TM) and a research assistant (EO) for the relevance of their titles and abstracts. The outcomes were compared and inconsistencies resolved to reach agreement on which articles would be read in full-text (n=88). The full-text articles were then independently assessed against the inclusion and exclusion criteria (see Table 2). The exclusion of a total of 63 articles was based on aim/focus (n=49), age (n=6), participants (n=3), evidence (n=2), design (n=1), article type (n=1), and language (n=1). Four additional records were identified by hand-searching reference lists of relevant articles and browsing database article suggestion boxes. Following consultation between TM and EO, a final list of 29 articles were included in the meta-synthesis (see Appendix D for the PRISMA flow of information diagram; Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).

Table 2

Article Inclusion and Exclusion Criteria

Study Aspect	**Inclusion Criteria**	**Exclusion Criteria**
Design	Qualitative methodology.	Quantitative studies and mixed-method studies that present predominantly quantitative results (i.e., more than half of the article results presents quantitative findings).
Aim/study focus	To explore the subjective experience of patients and/or family members receiving bad news about cancer from a HCP. Explicitly mentions "bad news", "truth-telling", or "disclosure" or references getting news about diagnosis, prognosis, discontinuation of active treatment, recurrence, or palliative care/end-of-life transition.	Broad focus (e.g., cancer/supportive care, communication, information delivery, or decision-making) or is about non-disclosure or language barriers (i.e., bad news is not the main or explicit focus). The paper covers the whole cancer journey or a period of time in which receiving bad news from HCP is only a partial aspect of the findings.
Article type	Peer-reviewed journal articles.	Reviews, commentaries, editorials, theses, non-peer reviewed articles, and book chapters.
Language	English.	All other languages.
Participants	Patients with a diagnosis of cancer, and their family members. Studies that include non-cancer patients or HCP can be included if cancer patient data is extractable.	HCPs. The sample consists of more than 50% of patients with a non-cancer diagnosis or cancer patients with intellectual disability.
Age	Adults (≥18 years). The specific age range is provided, or participants are stated to be "adults".	Children and adolescents, or if unable to obtain age range.
Data and evidence	Subjective accounts with at least one direct quote supporting the findings.[2]	Not subjective accounts (i.e. based on recordings or researcher observations of consultations). No direct quotes.
Country	All countries.	

Note. HCP= Healthcare professional

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[2] Given the focus on synthesising reports of patients' and family members' subjective experiences, studies that took a discursive approach were not included. Synthesising the social constructionist literature would be a valuable future contribution to understanding the area of breaking bad news.

Quality Appraisal

Articles were appraised using the checklist proposed by Walsh and Downe (2006). This checklist was used because it was a synthesis of several existing checklists and designed for use within a healthcare research context. Studies were assessed to have 'met', 'partially met' or 'not met' each criterion. TM conducted the quality appraisal for the included articles. The criteria provided detail to the reader about the articles from which the findings arose, but was not the basis for excluding articles from the review. Table 3 outlines the criteria and a summary of the degree to which each criterion was met across the included articles. For the appraisal of each article across the appraisal criteria, see Appendix C.

Table 3

Summary of Quality Appraisal of Included Articles

Criteria	Description	Met	Partially	Not met
Scope and purpose	A clear statement of, and rationale for aims, contextualised by existing literature	27	2	0
Design	Design consistent with research aim, data collection stated and appropriate	15	14	0
Sampling strategy	Sampling method and sample is appropriate	16	6	7
Analysis	Analytic approach is appropriate for aims	21	8	0
Interpretation	The context taken into account, and data used to support the interpretation	7	18	4
Reflexivity	Researcher reflexivity is demonstrated	3	3	23
Ethical dimensions	Awareness of ethical concerns and commitment to ethical research practices	24	0	5
Relevance and transferability	Links made to relevant theories and explanations, limitations, and future directions	20	9	0

Study Characteristics

A standard template was used to summarise the aim, participants' characteristics, the country in which the study was conducted, data collection technique, methodology, bad news context, and cancer type of the 29 included articles (see Table 4 for a summary and Appendix E for full details). TM performed the extraction of study characteristics, which was checked by EO for accuracy. This yielded 92.72% agreement on the study characteristics extracted, and following consultation, all inconsistencies were resolved. At this stage, each article was assigned a code that is used throughout the review to denote when the preceding text related to a particular article (see Appendix F for article references and assigned codes; article codes also presented in Table 4).

Analysis

Data extracted from the 29 included articles comprised verbatim text about the bad news experiences of patients and their family members within the ‘results’ or ‘findings’, along with relevant text from the abstract, discussion and conclusion to capture any variation in reporting of results (Thomas & Harden, 2008). The data was imported into the online qualitative analysis software, Dedoose, to be managed and organised into themes.

Data were analysed according to the three stages of thematic synthesis outlined by Thomas and Harden (2008). Stage one was conducted independently by TM and EO and involved coding each line of data based on the content and meaning, often assigning multiple codes to sections of text. These codes were created inductively as the coding process progressed. Initially, ‘free’ codes without a hierarchical structure were assigned, but over time, a hierarchy was created to organise the codes. This line-by-line coding was the way concepts from the individual studies began to be synthesised (Thomas & Harden, 2008). Before moving to the next stage, excerpts from each code were reviewed for consistency and additional codes added where necessary. Stage two was developing ‘descriptive’ themes by grouping codes based on similarities and differences to form a hierarchical structure. After independently completing this stage, TM and EO then compared their analyses and consulted until an agreed-upon structure of themes was reached. Stage three was the development of ‘analytical’ themes, whereby meaning was inferred from the descriptive themes in order to go beyond the findings of the primary studies and address the aims of the review. This part of the analysis was cyclical in nature, whereby analytical themes were checked against initial descriptive themes for relevance and coverage, and then revised (Thomas & Harden, 2008). TM produced a draft of the analytical themes that was reviewed by EO, and through consultation, a final version was agreed upon.

Table 4

Summary of Study Characteristics

Code	Author	Year	Aim	Sample	Country	Data collection
A1†	Abazari et al.	2016	Explore perceptions and preferences of cancer patients, their families, physicians, and nurses in disclosing cancer diagnosis.	15 P 6 F	Iran	Interviews
A2†	Blakely, Karanicolas, Wright, & Gotlib Conn	2017	Understand the information needs and communication experiences of patients treated surgically for pancreatic cancer, and the perceived enablers and barriers to effective communication.	10 P 8 F	Canada	Interviews
A3†	Butow, Dowsett, Hagerty, & Tattersall	2002	Obtain patient and health professional views on optimal ways of presenting prognosis to patients with metastatic breast cancer.	17 P	Australia	Interviews
A4	Chen, Wang, & Tang	2018	Explore gender differences for patients with cancer in truth-telling and preferences for decision making.	20 P	Taiwan China	Interviews
A5	Chircop & Scerri	2017	Explore the lived experience of patients on receiving a diagnosis of non-Hodgkin's lymphoma.	6 P	Malta	Interviews
A6†	Deschepper et al.	2008	Describe attitudes towards truth-telling of terminal patients and professional caregivers, and barriers to full information exchange.	17 P 8 F	Belgium	Interviews
A7	Friedrichsen, Lindholm, & Milberg	2011	Explore the experiences and preferences of terminally ill cancer patients regarding truth-telling in the communication of poor prognosis.	45 P	Sweden	Interviews
A8‡	Friedrichsen, Strang, & Carlsson	2000a	Explore how patients with a disseminated cancer disease experienced the information about transition from a curable to an incurable state.	30 P	Sweden	Interviews
A9‡	Friedrichsen, Strang, & Carlsson	2000b	Explore how cancer patients in a palliative care setting perceive their participation and resources after receiving information about discontinuing active tumour treatment.	30 P	Sweden	Interviews
A10	Friedrichsen et al.	2001	Explore the experiences of family members when receiving information about ending tumour treatment in patients with incurable progressive cancer.	20 F	Sweden	Interviews
A11‡	Friedrichsen, Strang, & Carlsson	2002	Explore what significance verbal expressions had for cancer patients when given information about ending active tumour treatment.	30 P	Sweden	Interviews
A12†	Fujimori et al.	2005	Describe attributes of good communication with patients receiving bad news about cancer in Japan.	42 P	Japan	Interviews
A13	Furber, Bonas, Murtagh, & Thomas	2015	Explore how patients experience an initial oncology consultation.	5 P	UK	Interviews

A14†	Furber, Cox, Murphy, & Steward	2013	Investigate how doctors and patients diagnosed with advanced incurable cancer experience the disclosure of bad news.	16 P	UK	Interviews
A15†	Hanratty et al.	2012	To understand patients' perspectives on how a diagnosis of a life-limiting illness was first communicated to them.	31 P	UK	Interviews
A16	Hoff et al.	2007	Investigate patients' views of information during the trajectory of their disease.	12 P	Sweden	Interviews
A17	Kirk, Kirk, & Kristjanson	2004	Obtain feedback from palliative care patients and relatives from various ethnicities experience of disclosure and information sharing.	37 P 35 F	Australia, Canada	Interviews
A18	Lobb, Halkett, & Nowak	2011	Explore the views of patients and their caregivers on their experience of being diagnosed with high-grade glioma.	19 P 21 F	Australia	Interviews
A19	Mardani-Hamooleh & Heidari	2017	Explore the lived experiences of Iranian cancer patients when hearing bad news.	11 P	Iran	Interviews
A20	Maree, Langley, & Nqubezelo	2014	Explore the experiences of underprivileged women being confronted with a diagnosis of cervical cancer.	19 P	South Africa	Interviews
A21	Randall & Wearn	2005	Explore the experiences of patients with haematological cancer as they reflect on the process and content of receiving bad news.	15 P	UK	Interviews
A22	Ridgway et al.	2014	Explore how patients reacted to being told they have a 'good' cancer.	25 P	UK	Interviews
A23	Salander	2002	Analyse how patients with recently diagnosed cancer narrate the manner in which they received their diagnosis.	138 P	Sweden	Narratives, interviews
A24	Schaepe	2011	Analyse accounts of patients and their family members of learning of a cancer diagnosis.	28 P 30 F	USA	Interviews
A25†	Thorne, Oglov, Armstrong, & Hislop	2007	Extend our understanding of how prognostic communications are received and interpreted by patients.	200 P	Canada	Focus groups, interviews
A26	Thorne et al.	2010	Identify helpful communication during the diagnosis experience of cancer patients.	60 P	Canada	Interviews
A27	Tobin & Begley	2008	Explore the lived experience of receiving a cancer diagnosis.	10 P	Ireland	Interviews
A28	Valizadeh et al.	2012	Explore Iranian patients' experiences of cancer disclosure of their diagnosis.	20 P	Iran	Interviews
A29	Yardley, Davis, & Sheldon	2001	Document patients' views on the delivery of lung cancer diagnosis, their attitudes to methods used and ideas for improvements.	13 P	UK	Interviews

† Characteristics reported are of relevant participants only (i.e. cancer patient and/or family members), omitting health professionals and non-cancer patients.

‡ Same sample of patients

Note. P= Patients, F= Family members, UK= United Kingdom, USA= United States of America

Results

Description of Included Articles

The 29 articles that met the inclusion criteria were published between 2000 and 2018. Twenty-two of these articles presented patient experiences of receiving bad news, six included both patient and family member perspectives and one was of family members' experiences only. The data came from 861 different patients[3] (median=19; range=5 to 200) and 128 family members (median=20; range=6 to 30). For articles that reported the sex of patients (n=24) and family members (n=4), the majority were female (patients=484 female, 282 male; family members=49 female, 28 male). The age of participants ranged from 21 to 86 years based on 20 articles that reported this information. Data were collected from 12 different countries, including six studies conducted in the United Kingdom, five in Sweden, four in Canada, three in each Australia and Iran, and one in each of the United States of America, South Africa, Japan, Taiwan, Malta, Belgium, and Ireland. All studies collected data via interviews, with one study also using focus groups and another using written narratives. There were many cancer types represented across the articles and bad news given in the context of diagnosis, prognosis, discontinuing active treatment, recurrence, and transition to palliative/end-of-life care. The appraisal of the quality of the articles indicated that more of the criteria were 'met', than 'partially' or 'not met' (see Table 3); however, none of the articles met all the appraisal criteria. Researcher reflexivity was the criterion met the least and can often be excluded from publications due to word limitations, despite being a hallmark of qualitative research (Walsh & Downe, 2006).

Analytic Themes

It was evident from the articles that receiving 'bad news' was understood as a process that occurred over time, rather than a singular event, and that the lead-up, actual bad news and aftermath were significant in patients' and family members' experiences[A21,A23,A27]. As such, the results of this synthesis are presented based on three phases of the bad news process, labelled 'preparation',

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[3] Three studies[A8,A9,A11] used the same sample, so the participants were counted only once towards the presented characteristics.

‘delivery’, and ‘adjusting and coping’. Under each phase, a series of themes were identified that highlighted what was important to patients and family members during these phases. The order in which the themes appear does not reflect their importance or frequency across the included articles.

Preparation. The ‘preparation’ phase refers to prior arrangements, considerations, and engagements that occur before the actual news is delivered to the patient, even if only momentarily. There were four themes identified as significant for patients and family members during this phase: the setting, developing a relationship, knowing the patient, and forewarning.

The setting. Patients and family members wanted the news to be shared with them in a private,[A1,A12,A21] quiet[A1,A12] setting without distractions (e.g., HCPs’ communication devices turned off).[A12] Patients did not want to be alone when told bad news,[A5,A18,A23] appreciating an invitation ahead of time for family to be present, or arranging HCPs to be present for support.[A13,A23,A15] While patients and family members understood that HCPs were under time pressure,[A6] they nevertheless desired sufficient time during the bad news consultation so that the HCPs were unrushed.[A1,A5,A15,A21,A26] Being given time for the consultation meant that they could express their emotions, process the news, ask questions they may not think of immediately, and have everything explained.[A12,A17,A23,A26,A27] Getting the bad news face-to-face rather than via telephone was preferred;[A12,A18,A23] however, for those with a well-established relationship with their HCP, or who lived at a significant distance from the hospital, being told over the phone was acceptable.[A23]

Developing a relationship. The development of a relationship with their HCP was important as patients wanted to hear bad news from someone they knew and trusted.[A3,A12,A17,A24] Trust arose from having confidence in the HCP’s expertise,[A1,A2,A8,A17,A18,A21,A24] honesty in patient-HCP communication,[A1,A21] and seeing the human qualities of their HCP (e.g., being friendly, caring, and non-judgmental).[A2-4,A21,A26] Trust gave patients the belief that their HCP would act in their best interests[A4,A6] and made them feel supported and acknowledged by them.[A23] It was recognised that developing a relationship took time,[A8] but that patients’ and family members’ first impressions of their HCP mattered.[A24] Putting emphasis on building a good relationship at the start was important, as poor relationships tended to persist as problematic throughout the patient’s cancer journey.[A17]

Knowing the patient. It was acknowledged that every patient is different[A1,A12,A20] and the variation in patients' preferences for how bad news is told means there cannot be a 'one-size-fits-all' approach. There is variation in how much detail patients want to be told[A4,A16] and whom they want present.[A4,A29] Patients' and family members' cultural backgrounds informed their preferences, such as whether family took a primary role typically seen in non-Western settings, [A1,A12] or if the patient's choice in the degree of family involvement was emphasised, as is common in Western countries.[A13] Additionally, some patients' spirituality and faith were central in their lives and appreciated when this was recognised as significant to them.[A1]

To navigate this inevitable variation, it was important that HCPs took the time to establish the patient's and family's preferences to deliver bad news satisfactorily.[A6,A7,A13] Some patients expected that HCPs would be able to read them and know what, and how much, information was desired,[A1,A2,A6,A8,A16,A21] while others believed it was the patient's responsibility to be proactive and openly communicate their preferences.[A3] Regardless, knowing the patients' preferences prevented HCPs relying on assumptions about what was best for a patient[A14] and creating a mismatch between information provided and what patients desired to know.[A25] HCPs were also able to provide individualised, tailored care to patients by knowing their preferences, which was highly valued by patients by making them feel respected as a person and not merely a 'number' or 'case'.[A2,A8,A21,A22,A25,A26,A29] While most patients express a strong desire to know their diagnosis, greater ambivalence for full disclosure of poor prognoses arose as patients transition to palliative care.[A6,A7] As such, patients' preferences must be reassessed throughout the disease trajectory.[A13]

Forewarning. Providing a warning to the patient and family members of the possibility of bad news enabled them to be more mentally prepared for the news, making it easier to hear.[A11,A12,A29] Forewarning could come from HCPs in the form of gradual news delivered over time as results become available,[A6,A7,A15,A17,A24] a statement a few seconds before the news is spoken (e.g., "unfortunately, I don't have good news"),[A11,A20,A26] or actions taken (e.g., inviting the family to attend, sitting close to the patient).[A11,A15]

Delivery. The delivery phase refers to what was important to patients and family members during the actual delivery of bad news, that is, the moment when the words were spoken. Four themes were identified: emotional reactions, empathy not sympathy, active participation, and understanding.

Emotional reactions. Regardless of the nature of the bad news, strong emotional reactions were described when the news was delivered. Many patients and family members were ‘shocked’ to hear the word ‘cancer’[A5,A9,A13,A15,A17, A18,A20,A22,A23,A28,A29] or felt a sense of unreality or numbness[A18,A24] that made it difficult for the news to be processed.[A5,A9,A13,A18,A20,A22] For others, they recalled a strong sense of relief that they had an explanation for their symptoms and validation for their health concerns.[A5,A14,A27,A29] Emotional reactions were informed by whether the news was unexpected or not,[A5,A9] patients’ past personal and professional experience with cancer,[A5,A22,A28] culturally informed responses to cancer (e.g., public shame and stigmatisation),[A19] and the widespread discourse of cancer being synonymous with death.[A1,A5,A20,A24,A28] The words and manner used by HCPs also impacted how the patient reacted to the news, with a preference for HCPs using less emotive words[A8] and having a calm presence.[A21]

Empathy not sympathy. Patients wanted HCPs to deliver bad news with genuine empathy,[A1,A2,A8,A17-21,A23] as this reduced their distress[A19] and gave them a sense of warmth and safety that was important at that difficult time.[A8] Patients perceived HCPs as empathic when they communicated that they cared for them[A2,A17] and provided validation for their distress[A22] calmly and professionally.[A26] However, when HCPs expressed high sympathy (e.g., getting distressed and emotional), patients interpreted this as a sign of there being no hope for the future.[A8,A23,A26]

Active participation. Patients and family members talked about themselves taking an active role in the delivery of bad news, rather than being passive receivers of information. It was important to patients that they and their HCPs could participate in a two-way conversation when the news was delivered so that they could have their say, lessening the power imbalance.[A3,A26,A27] Patients did this through the questions they asked during the bad news consultation.[A7,A8,A9,A13,A16,A21] Family members actively participated by being present when news was delivered so they were fully informed,[A10] asking HCPs for specific information[A10] and advocating for the patient.[A21]

Understanding. Patients and family members wanted a clear understanding of the information that HCPs shared with them.[A2,A3,A11,A14,A17,A20] This did not necessarily mean using hard, blunt facts, but rather HCPs being honest[A3,A4] and taking the time to explain the information.[A11,A29] Some found it helpful when HCPs used visual aids in their explanations or provided information leaflets to take away.[A2,A21] Patients and family members identified that misunderstandings arose from the use of medical jargon, technical terminology and ambiguous terms,[A4,A6,A13,A22,A29] and preferred the use of plain language and layman's terms they understood.[A2,A12,A17,A21,A26,A27] Some patients wanted their HCPs to explicitly use the word 'cancer' so they had a clear understanding of their condition, even if this was difficult to hear.[A14,A26] Having a clear understanding created a sense of calmness,[A19] whereas a lack of understanding increased stress for patients and family members[A4] and led many to look elsewhere at potentially unreliable sources of information to answer their questions (e.g., internet, magazines).[A5,A22,A28] Misunderstandings persisted if patients did not seek clarification or if HCPs failed to check whether the information they shared was understood.[A13]

Adjusting and coping. This phase refers to the aspects that helped patients and family members to adjust and cope with the difficult reality and implications of being told bad news about cancer. Four themes emerged as important during this phase: hope, holistic support, being a protector, and on-going relationships.

Hope. Hope was identified as a crucial component of coping with bad news, regardless of the patient's stage of cancer.[A7,A14,A17,A21] It was acknowledged that hope was more challenging to foster in the context of non-curable cancer, [A7] but was seen as vital at that stage.[A2] Hope came in different forms based on the patient's stage of cancer,[A14,A17,A25] for example, those early on in the cancer journey hoped for a full recovery, while those at the later-stage hoped for good quality of life in the time remaining.[A11] Patients paid close attention to HCPs' verbal and non-verbal cues to indicate the level of hope;[A25,A26] particularly looking for an indication of what was realistic for them to hope for.[A1,A2,A7,A26]

Patients derived hope from a number of different sources, including HCPs talking about treatment options.[A12,A21,A23,A26,A29] the patient's personal belief in miracles,[A18,A25,A26] their faith, [A9] having trust in their doctor's expertise,[A2] not focusing on death when active treatment ended,[A11] and interpreting vague statements, such as "we will do everything we can" as suggesting hope at the end-of-life stage.[A11,A17,A18] Many patients conceptualised accepting their poor prognosis as the antithesis of hope,[A4,A13,A18] leading some to avoid discussions of death and to deny their ill health as a way to cope.[A13,A14,A16,A19] However, some believed they could accept their poor prognosis and also hold onto hope for a miracle.[A17]

Holistic support. Receiving support from multiple sources to address patients' physical and psychological needs was important as patients adjusted to hearing bad news.[A1] First and foremost, emotional support and comfort came from the patient's family, [A1,A4,A9,A13,A15,A19-21,A29] but when this was not available, HCPs were expected to fulfil this support role.[A5,A12,A29] Doctors were expected to be able to attend to the patient's physical disease as well as their psychological needs,[A8] with it being helpful for doctors to involve nurses, members of the wider team (e.g., counsellors) and support groups to help them achieve this.[A1,A12,A21,A26] The articles primarily focussed on support for the patient; however, support and empathy for family members was equally important, as some felt overwhelmed and alone when adjusting to the reality of the bad news.[A24]

Being a protector. Patients and family members both described themselves as taking the role of protecting each other from certain aspects of bad news to help with coping.[A10,A13,A29] In the context of late-stage cancer, the family often were the ones to communicate with HCPs and be told the full truth about the patient's condition. Family had the role of deciding what to share and withhold from the patient based on what they felt best supported them to cope.[A7,A17] Family members took the protector role seriously and spoke about having to hide their emotions to not appear 'weak' in front of the patient.[A10,A12,A24] When patients did not have family present with them at the consultation, they experienced anxiety about sharing the bad news with their family due to the negative impact it might have[A20] and, in some cases, did not tell their family the bad news as a way to protect them.[A13,A29]

On-going relationships. The continuity of the patient-HCP relationship was important for the patient to adjust to hearing bad news the first time, and increased their ability to cope if subsequent bad news was part of their cancer journey.[A1,A8,A21,A23,A29] An on-going relationship was signalled to the patient by the HCP organising follow-up appointments[A12,A21,A23] and statements such as "you can come back".[A11,A17,A18] These were internalised as messages of non-abandonment and were recognised as particularly important when patients transitioned to palliative care and feared abandonment would signal the end to all hope.[A11]

Discussion

This review presents a synthesis of qualitative studies exploring what was important to patients and family members when they reflected on their experience of being given bad news about cancer. This was the first time the qualitative literature on the experiences of patients and their family members has been synthesised in this manner, with a review on HCPs' perspectives already in publication (Bousquet et al., 2015). It was evident from the depth and detail of patients' and family members' accounts across the 29 included articles in this review that receiving bad news was a key part of their illness journey and remembered as significant.

Patients' and family members' experiences indicated that there were three key phases in the bad news process, labelled: 'preparation', 'delivery', and 'adjusting and coping'. These phases were shown to be relevant regardless of whether the patient received bad news about diagnosis, prognosis, recurrence, ending active treatment, or transition to palliative care. A phase-based approach to breaking bad news is not entirely new to the literature. The widely used SPIKES model to guide HCPs to deliver bad news identifies stages for HCPs to follow (Baile et al., 2000). Aspects of the commonly used SPIKES process reflect what patients and family members wanted in the 'preparation' and 'delivery' phases, but not the 'adjusting and coping' phase. This suggested that patients and family members see HCPs as having a role in supporting them to adjust to, and cope with, the implications of the bad news that may not be recognised in current Western delivery models used by HCPs. The three phases identified in the current review also indicated that patients and family members conceptualised getting bad news as a process, rather than a single moment in time. This was consistent with the findings of Bousquet et al.'s (2015) review of HCPs' perspectives, suggesting that the deliverers and receivers of bad news hold a similar view.

Patients and family members placed importance on their HCP attending to their psychological needs, as well as physical health. This was highlighted through patients' and family members' emphasis on receiving emotional support, empathy, instilling hope, and having a feeling of non-abandonment. It was unsurprising that patients looked for psychological support given the well-documented psychological impact receiving bad news can have (Mager & Andrykowski, 2002; Schofield et al., 2003). Given this finding, holistic models of healthcare that include attending to a patient's psychological wellbeing may apply to the bad news context over and above what a biomedical model of care can offer. However, this may be challenging as managing patients' and family members' emotions has been reported to be a source of discomfort for HCPs due to them perceiving a lack of training in this area (Monden et al., 2016) and having to concurrently manage their own emotional reactions (Bousquet et al., 2015).

This review found that patients and family members viewed having a relationship with their HCP as important throughout the bad news process. Forming a relationship facilitated trust and confidence in the HCP as part of patient's preparation for being told bad news and a sense of non-abandonment during the adjusting and coping phase. The therapeutic value of the patient- and the family-HCP relationship has been well recognised in the oncology literature, particularly in the context of advanced cancer, supporting this finding (Trevino et al., 2014; Trevino, Maciejewski, Epstein, & Prigerson, 2015; Zhang, Nilsson, & Prigerson, 2012). Bousquet et al. (2015) reported less emphasis on forming relationships with patients in HCPs' experiences of delivering bad news. It is possible that HCPs may not realise the extent to which the interpersonal aspect of the bad news exchange impacts on a patient's experience of getting bad news.

The studies in this review included patients with many different cancer types (see Appendix E). When looking at patients' experiences across different cancer types, there did not seem to be a notable variation. However, almost half of the included articles did not indicate the patient's cancer type alongside the themes and direct quotes, making this type of analysis challenging to conduct. What became apparent was that for articles involving breaking bad news about poor prognoses, having some form of hope and a trusting relationship with HCPs was commonly mentioned as important. While these variables were not exclusive to patients with terminal or late-stage cancer, it seemed that a patient's stage of cancer appeared to matter more than the type of cancer they had when it came to how they reflected in their experience of getting told bad news.

Across the reviewed articles, it was clear that the same approach to delivering bad news would not be suitable for every patient due to the variation in what individuals wanted when receiving bad news. This variation may be culturally informed, as reflected in models of breaking bad news that have been developed for different cultural settings (Salem & Salem, 2013; Tang et al., 2014). HCPs getting to know patients' preferences was therefore important, with most patients in the current review expecting HCPs to be able to 'read' them to ascertain what their preferences were. This conflicted with the views of some HCPs, who relied on patients to ask direct questions to determine what they wanted to know, assuming what patient did not ask, they did not desire to know (Bousquet et al., 2015). This mismatch between patients' and HCPs' expectations of how preferences are ascertained could mean the patient is not given the information they need.

This review found that institutional variables impacted patients' and family members' experiences of receiving bad news, the same result seen in qualitative studies of HCPs' perspectives (Bousquet et al., 2015) and quantitative data (Aminiahidashti et al., 2016). There was an importance placed on bad news being delivered in a quiet, private room with sufficient time so that the HCP did not appear rushed. This consistency is a reassuring confirmation that these issues are important to address.

Study Limitations

The current meta-synthesis had a number of limitations. Despite the systematic approach aimed at gaining a thorough coverage of the literature, the majority of the data came from the patient's perspective, reflecting the imbalance seen in the quantitative literature. It may be that the inclusion of only peer-reviewed journal articles limited access to family members' perspectives that may have been available in the broader literature, or could reflect a bias in the literature towards exploring patient experiences. Family members form an important part of the healthcare consumer perspective and therefore their perspectives are worthwhile understanding.

Additionally, while attempts were made to establish clear inclusion and exclusion criteria, a degree of subjectivity when selecting articles was inevitable. The involvement of a research assistant was used to address this; however, the primary author and the research assistant may have had similar perspectives given both had trained in psychology. Furthermore, the included articles were not all of high quality (see Table 3 and Appendix C) and the results should be interpreted with that in mind.

Clinical Implications

In meeting the second aim of the review, the implications of the review's findings are presented as a series of recommendations for future healthcare practice, training, and research (see Table 5). Practice-based recommendations identify healthcare institutions and individual HCPs as having a role in optimising breaking bad news; training suggestions reflect the importance of responding to patients' psychological wellbeing in providing more holistic healthcare; research recommendations focus on developing a greater understanding of family members' experiences.

Table 5

Practical Recommendations

Area	**Recommendations**
Healthcare practice	• Healthcare institutions provide rooms that are quiet and private for bad news conversations • Organise HCPs' work schedules to allow longer consultations when breaking bad news to avoid being rushed • HCPs prioritise building rapport when first encountering patients and establish the patient's individual preferences for how they want bad news to be delivered (including cultural considerations). • HCPs take a role in supporting patients and family members to adjust and cope with the bad news
Training	• Offer training to HCPs in responding to the expression of emotion and how to support patients' psychological wellbeing. • Inform HCPs of pathways to accessing additional support services for patients and family members, such as psychology and chaplaincy services.
Future research	• Address the underrepresentation of family member's experiences of bad news in the literature to better understand their needs and how to support them to cope.

Conclusions

The synthesis of experiences of patients and family members receiving bad news highlighted the significance of getting bad news and that it could be understood as a process with phases of 'preparation', 'delivery' and 'adjusting and coping'. Patients and family members placed great emphasis on having a relationship with their HCP and the HCP's role in attending to their psychological needs as they adjusted and coped with the news. Given the variation in patient preferences for how the news is delivered, HCPs had a role in ascertaining what these were for the individual patients they broke bad news to, not exclusively relying on patients to indicate what information they wanted. A clear finding, that is consistent across the literature, is the value patients and their family members place on having a quiet, private space for bad news to be delivered and sufficient time for the HCP to share this sensitive information.

CHAPTER THREE: REVIEW OF THE LITERATURE

Part Two:

Healthcare Professionals' Experiences of Delivering Bad News about Cancer

Healthcare professionals (HCPs) working in the area of oncology inevitably, and often regularly, face the challenging task of being the bearers of bad news to adult patients and their family members. Existing qualitative literature has explored HCPs' subjective experiences of delivering bad news, highlighting the many aspects HCPs need to consider when engaging in this specific type of communication. These considerations will be outlined below.

Finding the Balance

The complexity of delivering bad news is inherent in the balance that HCPs have to negotiate between multiple and competing factors, a finding reported by Bousquet et al. (2015) in their meta-synthesis of oncologists' perspectives on delivering bad news. The current review identified that HCPs experienced having to balance upholding their professionalism in the context of this emotionally impactful task, walking the line between being honest and maintaining hope, and weighing up a patient's right to autonomy when their family's wish was for non-disclosure.

Emotionality and professionalism. HCPs recognise that the process of breaking bad news to patients and family members about cancer can be a personally emotional experience (Bousquet et al., 2015). However, they reported having to balance their emotionality with maintaining professionalism. Friedrichsen and Milberg (2006) explored Swedish physicians' concerns about their level of emotionality when breaking bad news to terminally ill cancer patients. Physicians reported that delivering news of incurable cancer conflicted with them self-identifying as a 'healer', and they experienced guilt for not having done enough or living up to the expectations of their patients. The importance HCPs place on controlling their emotions was reflected by patients, who did not want their HCPs to appear distressed when delivering bad news, as this signalled to them that there was no hope (Matthews, Baken, Ross, Ogilvie, & Kent, 2019).

Balancing emotionality and professionalism was reported as particularly challenging for HCPs in the context of discussions about transitions to end-of-life, death and dying. Nurses reported that having developed relationships with their patients made it more emotionally difficult for them to discuss death (Banerjee et al., 2016), especially when having end-of-life discussions with younger patients (Mishelmovich, Arber, & Odelius, 2016). A study reported that HCPs' difficulty with conversations of this nature could arise from their own fear and discomfort with death (Banerjee et al., 2016). In exploring this phenomenon, Rodenbach, Rodenbach, Tejani, and Epstein (2016) found that HCPs who had come to terms with their own mortality were more open and comfortable with discussing death. Many HCPs viewed accepting their own mortality as important in the care of patients with terminal cancer because having challenging discussions about death was part of fulfilling their professional role (Wenrich et al., 2001).

HCPs reported utilising several cognitive and avoidance/detachment strategies to uphold their professionalism in the face of this emotionally challenging task. Shaw, Brown, and Dunn (2013) reported that some Australian trainees and senior doctors focused on being well-prepared, reframing bad news as a positive step towards accessing treatment, and having realistic expectations of themselves as a means to cope. The authors also reported that some avoided giving bad news, selected patients to care for with better prognoses, focused on the technical details rather than the emotions of the encounter, and presented as distant and objective (Shaw, Brown, & Dunn, 2013). Physicians from India used their faith to distance themselves from feeling blamed when treatment failed (Martis & Westhues, 2015). Studies have found that nurses also attest to maintaining a degree of detachment from their patients to prevent emotions, such as sadness, compromising their ability to be empathetic and support their patients when present for the delivery of bad news (Banerjee et al., 2016; Dunniece & Slevin, 2000). There is a risk, however, that becoming too distant could result in HCPs being perceived as non-empathic by patients who wanted their HCPs to communicate that they cared for them (Matthews et al., 2019). The importance of HCPs responding empathically will be discussed later in this review.

It is evident from HCPs' and patients' perspectives that HCPs effectively managing their emotions, rather than avoiding the task or being too distant, is a key component of delivering bad news in a professional manner. Interestingly, existing models used to guide HCPs to break bad news (see Table 1) do not consider the emotionality of the HCP in the process. These models may be developed on the assumption that a HCP will not be personally affected by delivering bad news, which is not reflective of their reported subjective experiences.

Honesty and hope. In Western cultures, such as New Zealand, patients have the right to honest communication from their HCPs so they are fully informed about their medical condition (Health and Disability Commissioner, 2019). In the context of delivering bad news about cancer, patients reported that honesty from their HCPs was a way they developed trust in them (Matthews et al., 2019). However, there is consensus among HCPs and patients that honesty should be balanced with sustaining hope, as hope was crucial at all stages of the cancer journey (Bousquet et al., 2015; Matthews et al., 2019). HCPs spoke about deliberately creating hope for patients, even when their condition was palliative (Mishelmovich et al., 2016), by constantly re-negotiating the focus of hope, as the goals of care shifted with disease progression (Brown, Goliath, van Rooyen, Aldous, & Marais, 2017; Clayton, Butow, Arnold, & Tattersall, 2005b).

HCPs perceived that being honest in the context of delivering bad news did not mean being blunt or insensitive (Clayton, Butow, Arnold, et al., 2005b; Wenrich et al., 2001), and providing hope did not mean lying or giving false hope (Blakely et al., 2017). Indeed, HCPs emphasised that finding the balance between honesty and hope came from ensuring that patients held realistic hope for an outcome that could be reached given their stage of disease, tempering patients expectations if they were unrealistic (Butow et al., 2002; Gordon & Daugherty, 2003).

HCPs reported that it was particularly challenging to offer hope in the context of delivering honest news to patients about poor prognoses (Blakely et al., 2017; Gordon & Daugherty, 2003). Patients similarly found it difficult to maintain hope when being told they had a limited life expectancy, with some perceiving that holding hope and accepting a poor prognosis were in opposition (Matthews et al., 2019). As such, HCPs expressed fears that full disclosure of a terminal prognosis might destroy all hope for the patient and negatively impact their psychological wellbeing (Ehsani, Taleghani, Hematti, & Abazari, 2016). This perspective was endorsed by HCPs from Iran, who reported the fear of causing harm to patients as the justification for non- or partial-disclosure of diagnostic and prognostic information; they preferred to use vague terminology rather than the word ‘cancer’ when talking to patients and share full information with family members (Abbaszadeh et al., 2014; Beyraghi, Mottaghipour, Mehraban, Eslamian, & Esfahani, 2011; Valizadeh et al., 2014; Zamanzadeh et al., 2013).

Non-disclosure in the oncology setting was not limited to Iran, with Furber et al. (2013) reporting that doctors from the United Kingdom (UK) avoided discussing prognoses unless directly asked, for fear of putting patients into a negative mind-set. Reflective of HCPs' uncertainty about how much to share about poor prognoses, patients were also more ambivalent about knowing full information as their disease progressed to palliation, compared to the certainty they had about wanting to know their diagnosis at the start of their cancer journey (Matthews et al., 2019).

HCPs reported using multiple strategies to balance honesty and hope. Gordon and Daugherty (2003) found that oncology doctors in the US fostered hope by offering all available medical and non-medical treatments, being optimistic about the constant development of new treatments, and communicating their commitment to offering all they could. Patients also reported deriving hope from being given treatment options, paying close attention to HCPs' verbal and non-verbal cues to signal what they could realistically hope for (Matthews et al., 2019). HCPs who shared with their patients the possibility of them being a statistical outlier (Gordon & Daugherty, 2003) may help patients develop a belief in a miracle that, for some, evoked hope (Matthews et al., 2019). In the palliative care context, when the focus of hope shifted, HCPs emphasised hope for effective symptom management, in addition to offering their patients practical equipment and psychological support (Clayton, Butow, Arnold, et al., 2005b; Friedrichsen & Strang, 2003).

Studies reported that HCPs perceived that the type of information given to patients when delivering news of poor prognoses was a key consideration in regards to sustaining hope. HCPs reported that it was important to inform their patients that their lifespan was limited due to their cancer, but most preferred to not give specific statistics about life expectancy, in the fear that this would destroy their hope (Clayton, Butow, Arnold, & Tattersall, 2005a). HCPs expressed the belief that many patients had limited understanding of percentages (Gordon & Daugherty, 2003) and that giving these could cause patients to focus on survival rather than their quality of life (Butow et al., 2002). A study exploring how HCPs manage the interaction between hope and patients' desire for prognostic information reported that getting to know their patients over time helped them to strike the right balance for each patient (Curtis et al., 2008).

Patient autonomy and family wishes. In synthesising family members' experiences, it was found that, particularly in late-stage cancer, family took on a protective role by being the ones to know the full truth about the patient's condition and communicating directly with HCPs (Matthews et al., 2019). HCPs reported having to manage honouring family members' wishes for information to be withheld from the patient, with balancing the patient's autonomous right to information. HCPs said that it was common practice in Greece (Oikonomidou et al., 2017) and Iran (Ehsani et al., 2016; Valizadeh et al., 2014) for them to deliver bad news to the patient's family first, who would then decide how much information they would share with the patient, or if they would make this disclosure. This can be seen as conforming to a family-centred care model (Naseem, 2018).

Studies from Western countries have also explored the issue of balancing patient autonomy with family wishes for HCPs. Butow et al. (2002) found that Australian HCPs worked on building trust with family members and convincing them that it was best to have open discussions of prognosis with patients. If family members insisted on non-disclosure in a palliative care setting, Clayton, Butow, and Tattersall (2005a) reported that some Australian HCPs respected the family wishes, but would answer any questions honestly if asked directly by the patient.

The Healthcare Professional-Patient Relationship

Establishing a relationship with the patient and their family members was seen as important to doctors and nurses to sensitively deliver bad news. HCPs spoke about positive relationships involving the patient trusting them, which allowed them to have difficult conversations about the future in a palliative care setting (Clayton, Butow, & Tattersall, 2005b; Mishelmovich et al., 2016). This was consistent with patients' perspectives, who desired hearing bad news from a HCP they had a trusting relationship with (Matthews et al., 2019). When it came to delivering bad news about poor prognoses, Australian HCPs reported how helpful it was to have a long-standing relationship with their patient; this relationship enabled them to know their preferences for how, and what, information was shared, their social support network, and coping skills, as well as having the opportunity to foreshadow the possibility of bad news early on (Butow et al., 2002).

HCPs advocated for spending time with the patient to facilitate a trusting relationship, along with answering patients' questions, having continued contact, offering emotional support, listening, having a warm and gentle manner, and being unhurried (Blakely et al., 2017; Clayton, Butow, & Tattersall, 2005b; Elit et al., 2015; Oikonomidou et al., 2017). Patients were found to have a similar view of what helped establish a relationship. They agreed that relationships took time to build, but also perceived that their first impression of their HCP influenced the nature of the relationship they went on to develop (Matthews et al., 2019). Even if the first point of contact with a HCP was in the consultation that bad news was delivered, Irish nurses reported that sharing the experience of first hearing bad news with the patient had the potential to make the nurse-patient relationship stronger (Dunniece & Slevin, 2000).

There were, however, a number of factors HCPs reported as complicating the formation of a relationship with their patients. Three studies of nurses' experiences consistently reported how problematic it was to the nurse-patient relationship when the nurse was told information before the patient was informed, as it was not their role to disclose that information (Banerjee et al., 2016; Dunniece & Slevin, 2000). This created a power imbalance that strained the openness of their relationship with the patient (Mishelmovich et al., 2016). Physicians mentioned how challenging navigating language barriers and the use of an interpreter can be for forming a doctor-patient relationship (Friedrichsen & Milberg, 2006). While HCPs' recognition of the benefits of a positive HCP-patient relationship was evident, physicians also expressed fears of not being able to control their emotions and losing their objectivity if they did develop close relationships with patients (Friedrichsen & Milberg, 2006). This could be seen as part of HCPs' need to balance their emotionality and professionalism when delivering bad news.

The centrality of the HCP-patient relationship evident in this review was not emphasised in Bousquet et al.'s (2015) meta-synthesis of oncologists' perspectives on delivering bad news. It is possible that the exclusion of nurses' perspectives in their study contributed to this, as the importance of forming relationships within the current review often came from studies that interviewed nurses (e.g., Banerjee et al., 2016; Dunniece & Slevin, 2000; Mishelmovich et al., 2016). Many of the studies in the current review are more recent publications of doctors' perspectives (e.g., Blakely et al., 2017; Oikonomidou et al., 2017) than those included in Bousquet et al.'s (2015) review, which may suggest an increase in focus for doctors on the HCP-relationship when delivering bad news in recent times.

Patient-Centred Care

Approaching the breaking of bad news by tailoring the delivery to an individual patient's needs was seen as an appropriate manner of disclosure by HCPs across different countries, including South Africa (Brown et al., 2017), Greece (Oikonomidou et al., 2017), Iran (Abazari et al., 2016), and the UK (Mishelmovich et al., 2016). This method, commonly labelled a patient-centred approach, emerged out of HCPs establishing a relationship with the patient in which they explored the patient's personal fears, concerns, preferences, and coping strategies (Brown et al., 2017). It was found that patients also wanted individualised care, reporting that this made them feel seen as a person and not just a number or medical case (Matthews et al., 2019).

Fröjd, Lampic, Larsson, Birgegård, and Von Essen (2007) reported that Swedish doctors paid close attention to verbal (e.g., questions asked) and non-verbal (e.g., body posture, facial expression) behaviours to assess how much information the patient desired. This was consistent with the expectations of most patients, who were found to expect HCPs to read what their preferences were, rather than the onus being on them to signal what information they wanted (Matthews et al., 2019). Variables, such as the patient's age, health status and education level, were reported by Oikonomidou et al. (2017) to inform how Greek HCPs individualised their delivery of news. Doctors reported delivering less direct and more limited information when breaking bad news to older patients, those with mental health difficulties, and those with lower education status (Oikonomidou et al., 2017). Both patients and HCPs reported that patient-centred care also meant being cognisant of changes in a patient's preferences over time as their disease progressed (Butow et al., 2002; Matthews et al., 2019).

Cultural and Spiritual Considerations

As part of providing individualised care to a patient, HCPs mentioned being open to diversity in patients' cultural and spiritual beliefs and adapting their practice accordingly. In a study by Brown et al. (2017), South African HCPs reported their experience of delivering bad news to

Zulu patients. They demonstrated their openness by using Zulu phrases, referencing Zulu cultural health beliefs and showing a genuine interest in spiritual practices that patients wanted to be part of their care. The authors referred to this as ‘cultural-centred communication’, where cultural narratives were actively incorporated into their delivery of bad news, rather than HCPs simply being aware of potential cultural differences (Brown et al., 2017). In being sensitive to the cultural interpretation of cancer as a taboo subject in Iran, adapting the word ‘cancer’ to words with less negative connotations (e.g., mass or tumour) when talking with patients, was once again relevant. The aim was to lessen patient distress, as cancer is considered synonymous with death and suffering in Iranian society (Abazari et al., 2016).

In India (Martis & Westhues, 2015) and Iran (Abazari et al., 2016), HCPs reported the important role that spiritual beliefs play in helping patients to cope with the news of their cancer. Martis and Westhues (2015) described HCPs directly exploring patients’ spiritual beliefs to assess whether this would be a resource they could use to console the patient and foster hope. Drawing on Indian patients’ faith when in the terminal phase of their cancer was particularly helpful, as HCPs perceived that their belief in life after death lessened their distress (Martis & Westhues, 2015). Patients reported appreciating when HCPs were able to recognise that their faith was important to them and incorporate this into the delivery of bad news (Abazari et al., 2016). Considering a patient’s faith could be seen as part of patients’ desire for holistic healthcare from their HCPs that goes beyond a focus on physical illness (Matthews et al., 2019).

Responding Empathically

In the reviewed studies, HCPs recognised that receiving bad news is a highly emotional experience for patients and their family members, which requires them to respond empathically. Both doctors and nurses reported that empathy arose from putting themselves in their patients’ shoes and imagining how their experience might be (Dunniece & Slevin, 2000; Oikonomidou et al., 2017). Some HCPs spoke about it being helpful to get an understanding of what the patient knows about their illness to facilitate seeing the situation from the patient’s perspective (Mishelmovich et al., 2016), while others reported that having personal experience with receiving bad news was useful in empathising appropriately (Oikonomidou et al., 2017).

Being empathetic, however, could be complicated by HCPs identifying too strongly with their patients, a concern raised mainly by nurses in the literature. Nurses from Ireland (Dunniece & Slevin, 2000) and the USA (Mishelmovich et al., 2016) experienced greater emotionality and concerns about their own mortality when their patients were the same age as them. A further challenge for responding empathically (identified by nurses working in an end-of-life setting) was when patients were angry, disrespectful towards staff, unable to accept the reality of their disease, or unwilling to communicate openly with them (Banerjee et al., 2016).

Facilitating Patient Understanding

The meta-synthesis presented in *Part One* of this chapter found that patients and their family members wanted a clear understanding of the patient's illness (Matthews et al., 2019). HCPs have been reported to place similar importance on this and felt that they were responsible for facilitating this understanding (Blakely et al., 2017).

HCPs used various methods of explaining the meaning of the bad news to patients. Brown et al. (2017) reported that HCPs helped patients to reach an understanding by using images to support their verbal explanations, referencing the stages of cancer to explain the implications of their disease, and using analogies or metaphors the patient could relate to. Studies of HCPs from Australia (Butow et al., 2002) and Canada (Elit et al., 2015) identified that some HCPs preferred to explain prognoses and cancer recurrence using numbers, while others preferred the use of analogies, suggesting that there was no consensus approach to this task. While the meta-synthesis did not clarify patients' perspectives on hearing exact prognostic numbers, there was, however, consensus among most HCPs and patients that medical jargon should be avoided in HCPs' communication with patients (Blakely et al., 2017; Matthews et al., 2019).

Judging a patient's level of understanding was a complicated, but important, part of delivering bad news. Blakely et al. (2017) reported that some Canadian surgeons found it difficult to judge a patient's level of understanding and, indeed, even identify what constituted 'understanding'. These HCPs said that they felt satisfied the patient 'understood' if the patient was made aware of the potential complications, risk of recurrence, and the chance of cure (Blakely et al., 2017). However, HCPs were mindful that not all information they explained to patients would be absorbed, due to variables such as a patient's level of pain or heightened emotionality (Butow et al., 2002). As such, HCPs reported that it was valuable to check with the patient what their understanding was and what information they recalled (Brown et al., 2017).

The Role of Family

The involvement of patients' family members during the process of receiving bad news about cancer was seen as 'pivotal' by HCPs (Datta et al., 2017), reflecting the importance placed on the family by patients (Matthews et al., 2019). HCPs spoke about wanting a patient's family to be involved from the beginning (Beyraghi et al., 2011) and present in bad news consultations (Clayton, Butow, & Tattersall, 2005b). HCPs viewed family as key supporters for the patient's psychological wellbeing (Datta et al., 2017; Oikonomidou et al., 2017) and able to help the patient process information after consultations (Elit et al., 2015). In their synthesis of the literature, Bousquet et al. (2015) conceptualised family as being facilitators for efficient delivery of information for the aforementioned reasons, but also as a potential barrier if the family had difficulty accepting palliation or desired limited disclosure of information to the patient.

It appeared that HCPs largely viewed family as a resource within the breaking bad news process. While family members are no doubt important in providing support and facilitating the transmission of information, it was identified that family have emotional reactions to hearing bad news, much like patients do, but often feel unable to express these in an effort to not appear weak in front of the patient (Matthews et al., 2019). Given this, HCPs may need to offer support to family members in all instances, a step identified in some guidelines for breaking bad news (e.g., Rabow & McPhee, 1999; Villagran et al., 2010).

A Team Approach

Many HCPs endorsed the importance of the involvement of the multidisciplinary team (MDT) in the process of delivery of bad news. This included the crucial role of nurses and allied HCPs such as psychologists and social workers (Abazari et al., 2016; Butow et al., 2002; Oikonomidou et al., 2017). Findings from a synthesis of the literature point to patients wanting their psychological, as well as their physical, needs attended to when given bad news (Matthews et al., 2019), which could be achieved through the involvement of the MDT. HCPs saw there being clear roles that members of the MDT took when collaborating on delivering bad news. There was consensus across HCPs from Iran (Abazari et al., 2016; Abbaszadeh et al., 2014; Beyraghi et al., 2011), the UK (Mishelmovich et al., 2016) and Australia (Clayton, Butow, Arnold, et al., 2005a) that the doctor was the one responsible for delivering the news and other HCPs came alongside in a support role.

The literature, however, indicates that there are a number of barriers faced by nurses in becoming involved in the bad news process. It has been reported that nurses are often excluded from the process of delivering bad news, and if they are included, they are not given sufficient information or time to prepare (Tobin, 2012; Warnock, Tod, Foster, & Soreny, 2010). Nurses can also experience competing demands on their time and may find it difficult to obtain coverage for their responsibilities while assisting with the delivery of bad news (Bowman, Slusser, & Allen, 2018). In response to some of these barriers and the need for adequate preparation of the multi-disciplinary team, Bowman et al. (2018) reported a nurse-led initiative to develop a collaborative process model for breaking bad news in an oncology setting. The outcome was an increase in notifying nurses when the delivery of bad news was being planned and the inclusion of nurses when bad news was shared. This study demonstrated that, along with communication and support expertise, nurses have an important role to play in the coordination of a collaborative and successful delivery of bad news to patients (Bowman et al., 2018).

It was evident in the reviewed literature that HCPs had a concept of what contributed to a successful team approach. Butow et al. (2002) reported that the success of the MDT came from the consistency of information across all team members, as inconsistent messages could confuse patients and compromise their trust in the team. In support of this, Brown et al. (2017) found that disjointed communication within the MDT, as well as poor documentation of what information the patient had been told and their level of understanding of that information, hindered working effectively as a team. However, when the team collaborated effectively, doctors from Greece reported a greater provision of support, attention and care for the patient, and the ability to draw on the expertise of specific specialties in the team (Oikonomidou et al., 2017).

Lack of Training

A lack of formal training was a common concern for HCPs in the reviewed literature, which led many to feel a perceived sense of incompetence in carrying out the complex task of delivering bad news (Brown et al., 2017; Ehsani et al., 2016; Oikonomidou et al., 2017). Friedrichsen and Milberg (2006) reported that Swedish physicians feared that their lack of skill would mean they said or did the wrong thing when delivering bad news to terminal cancer patients, which might upset patients or create misunderstandings. Banerjee et al. (2016) reported a similar experience for nurses working in the USA, who felt they did not have adequate communication skills when talking about transitions to palliative care, particularly around what the right thing to say was, and competently addressing patient fears and emotions. HCPs had to rely on an apprenticeship model of learning, through observing senior clinicians (Datta et al., 2017) or a process of trial and error, where experience became the teacher (Dunniece & Slevin, 2000; Griffiths, Ewing, Wilson, Connolly, & Grande, 2015; Mishelmovich et al., 2016).

Driven by their perceived lack of competency in communication skills related to breaking bad news, many HCPs reported the need for further training in this area. However, HCPs recognised that being trained to deliver a one-size-fits-all or recipe-based approach would not suffice (Datta et al., 2017; Mishelmovich et al., 2016). Patients' circumstances and reactions differ; thus, HCPs called for training in how to assess patient and family preferences for what, and how, the news is delivered and to deal with varied emotional reactions (Oikonomidou et al., 2017).

Some HCPs indicated that they needed training in domains beyond biomedicine. In countries where HCPs report that spirituality and faith are a significant component of the delivery of bad news, training in how to incorporate this dimension into clinical work was desired, as this was not offered to HCPs during their medical education (Martis & Westhues, 2015). In a study exploring the role of family members in bad news encounters, Indian oncologists felt that training was important in how to manage multiple family members, as well as the patient, when delivering bad news (Datta et al., 2017). Delivering skills in areas beyond attending to the physical treatment of an individual patient could be seen as moving towards 'holistic care', which was found to be important to patients when receiving bad news (Matthews et al., 2019).

Organisational Constraints

It was evident across studies that HCPs perceived there to be organisational variables that impacted on the quality of their delivery of bad news (Bousquet et al., 2015; Brown et al., 2017; Oikonomidou et al., 2017). The key resource constraints consistently mentioned across different oncology settings were time and private space, two variables that patients also reported as important to them when receiving bad news (Matthews et al., 2019). For HCPs, Brown et al. (2017) and Banerjee et al. (2016) reported that limited time meant that nurses were not able to sit with their patients while they adjusted to the news, which may compromise the quality of care they could offer patients. Time constraints also impacted team communication, resulting in not all HCPs in the MDT being able to be present for meetings (Brown et al., 2017). In regards to having a private space in which to deliver bad news, HCPs viewed this as important; however, this was not always possible when the design of the ward had patients in a four-bedded room (Abazari et al., 2016; Elit et al., 2015).

HCPs' high workloads were also frequently reported as problematic, resulting in HCPs having limited time with patients and experiencing personal fatigue (Ehsani et al., 2016; Oikonomidou et al., 2017). In such circumstances, HCPs reported that their interactions with patients became focused on clinical symptoms, at the expense of effective and empathetic communication (Banerjee et al., 2016; Ehsani et al., 2016; Oikonomidou et al., 2017). As one physician said, being overworked made him "a poor human doctor, or fellow human being, you could say" (Friedrichsen & Strang, 2003, p. 571). Patients reported the value of seeing the human qualities of their HCPs, such as being friendly and caring, for developing a trusting relationship (Matthews et al., 2019); therefore, HCPs being overworked potentially compromised HCP-patient relationships.

Summary

The process of delivering bad news to patients requires HCPs to consider, and balance, many factors, making it unsurprising that it is considered one of their most challenging tasks. HCPs working in the area of oncology reported having to find the balance between emotionality and professionalism, honesty and hope, and patient autonomy and family wishes; factors that often presented as discordant. HCPs spoke about the importance of forming a relationship with their patients and providing patient-centred care to meet their patients' individual needs. HCPs saw their role as responding empathically when bad news was delivered and helping the patient to understand their condition and its implications. Careful consideration was given to the crucial role family members take and how the healthcare team could work together to provide care to patients. HCPs also perceived a lack of training and organisational variables as compromising their ability to deliver bad news optimally.

Across the current qualitative literature on the experiences and perspectives of patients, patients' family members, and HCPs, there are several areas that can be further developed. These gaps will be outlined in the final part of this chapter.

CHAPTER THREE: REVIEW OF THE LITERATURE

Part Three:

Critique of the Current Literature

The corpus of qualitative literature reporting the subjective experiences of patients, their family members, and healthcare professionals (HCPs) comprises studies from a number of different countries and stages of cancer care (e.g., diagnosis, prognosis, end-of-life transition). By reviewing the existing research, suggestions can be made for what would be beneficial to include in future research, as well as gaps that could be filled. This critique forms *Part Three* of the current chapter and is presented below.

The review of the literature exploring doctors' and nurses' experience of the breaking bad news process highlighted aspects pertinent to their different roles. The consensus across the literature was that it is the doctor's responsibility to deliver the bad news to patients, whereas nurses are present alongside in a support role. It was, therefore, unsurprising that studies presenting nurses' perspectives emphasized building and maintaining relationships with patients and family, and the impact on these relationships of not being able to discuss new information until the doctor had fulfilled his role of disclosure. Conversely, doctors' main concerns were related directly to their role of delivering bad news and judging what, and how, the information would be shared. Doctors were also the ones to frequently report concerns about maintaining professionalism in the face of this emotional task, possibly reflecting the expectation of upholding objectivity. Given this variation, future research should include both the perspectives of doctors and nurses to capture the variation that might be present and enable role-specific recommendations to be made, if relevant.

Patients' family members are consistently mentioned as crucial to the process of breaking bad news; however, in the meta-synthesis in *Part One* of this chapter, it was shown that more studies have explored the experience of patients when receiving bad news than their family members (Matthews et al., 2019). Indeed, only one study by Friedrichsen et al. (2001) exclusively asked family members about their experience of receiving bad news. In the six studies that included family members' perspectives alongside the patient's, the number of family members interviewed was fewer than patients in all but one study (see Table 4 in *Part One* of this chapter).

The literature review in *Part Two* also demonstrated limited considerations made by HCPs for the specific needs of family members during this process, with the majority of HCPs viewing family members as a resource for patient support and understanding information. While it is understandable that the patient is prioritised in the delivery of news about their cancer, the impact on family members should not be overlooked. As such, future research should include family members as participants in qualitative studies to ensure that their experiences are better represented in the literature. Developing this understanding would highlight family members' needs when bad news is delivered to their loved ones and support recommendations to be made for how HCPs could best meet those needs.

Reviewing the literature illustrated that breaking bad news is a challenging and complex process for all those involved, making it valuable to obtain the perspectives of patients, their family members, and HCPs. Previous qualitative studies have included the perspectives of patients, family members, and HCPs as part of the same investigation, which allowed comparisons to be made in the experiences of these different groups across a number of patient cases of breaking bad news (e.g., Abazari et al., 2016; Datta et al., 2017; Ehsani et al., 2016). While these across-case comparisons are well-represented in the literature, little is known about what would be found from within-case comparisons. To achieve this, future research could gather the perspectives of each party in relation to the same patient's case of receiving bad news.

In summary, suggestions for future research arise from doctors and nurses having distinct roles and some variation in their experiences of the process, family members' perspectives being underrepresented in the current literature, and a lack of within-case comparisons in the experience of the different parties involved in the breaking of bad news. These research gaps have formed part of the basis for the development of the current study in this thesis, which will be outlined in the next chapter.

CHAPTER FOUR: THE CURRENT STUDY AND METHODOLOGY

This chapter provides an outline of the current study presented in this thesis. It begins by explaining the rationale for the study and outlining the study's aim and key research objectives. The theoretical underpinnings of the study will be described, locating it broadly within a qualitative approach, and specifically within interpretative phenomenological analysis. The rationale for, and nature of, consumer involvement in the current study will be explained, followed by the ethical and cultural considerations pertinent to conducting this study. The study's method will then be detailed, outlining the process of engagement and consultation with the study's advisory group, participant selection, and data collection procedure. The chapter will end with the data interpretation process that was followed.

Rationale for the Current Study

The design of the current study was informed by what is known about the breaking of bad news from the existing literature, the gaps that are yet to be filled in the research, and the interests of those who were part of the project's origins. The way in which these aspects are woven together in the current study is explained below.

The existing literature highlights the value of understanding the perspectives of the different parties involved in the process of breaking bad news; this is a challenging process for everyone involved, and there appears to be some variation in what is important to each party. To account for this, the current study will include the experiences of patients and their family members receiving bad news and doctors and nurses delivering this news. Including family/whānau members' perspectives attends to the underrepresentation of this group in the literature, and the outcome of the 2014 Otaki hui that highlighted the need for greater recognition of the role of family/whānau in the breaking bad news process (see Chapter One). The rationale for hearing from doctors and nurses stems from the literature suggesting some variation in healthcare professionals' (HCPs') experiences based on their different roles when delivering bad news (see *Part Three* of Chapter Three).

While reporting the perspectives of the different parties involved in the bad news process is not new to the literature, comparisons have been limited to those made across different patient cases of breaking bad news. In response to this, the current study will develop and apply a 'linked case' study design that allows the direct comparison of experiences of all those involved in a single patient's case of breaking bad news: the patient, their family/whānau member(s), and the HCPs. This will allow the perspectives of all those involved to be directly compared in relation to issues of importance during the breaking bad news process.

Additionally, there is a limited understanding of what is important to those involved in the process of breaking bad news in New Zealand. Research that has been conducted thus far on the topic within the New Zealand context includes a brief report on the perceptions of patients receiving a diagnosis of cancer in Dunedin Hospital (Merriman, Perez, McGee, & Campbell, 1997), an unpublished ethnographic study exploring what influences the process of communicating bad news in Tauranga Hospital (Deighton, 2013), and an article recommending a culturally appropriate approach to truth-telling among Asian patients living in New Zealand (Windsor et al., 2008). As such, the current study looks to contribute to a foundational understanding of how the process of breaking bad news is experienced in New Zealand, including both Māori and non-Māori perspectives to reflect New Zealand's bicultural context.

The current study needed to align with the interests of those who were involved in the project's inception. Firstly, this involved including the Māori community of Otaki, who was present at the 2014 hui in which the idea for the project arose, in the study's development, execution and outcome. As such, this group was consulted and involved in the project (see Otaki advisory group) and members of the community were given an opportunity to be participants in the study to have their voices heard. Secondly, this involved considering the goals of the Cancer District Group (CDG) who were also part of the 2014 hui. The CDG and hui were linked to MidCentral District Health Board (MDHB) and the cancer services it provides, so all participants in the current study were employed, or cared for, by services provided by MDHB. The CDG was particularly interested in the breaking bad news processes followed in the surgical departments at Palmerston North Hospital; thus, participants were surgeons and nurses from the surgical departments and the oncology patients and family members they saw. Limiting the participant group to one District Health Board and speciality (surgery) meant recommendations could be made from the current study that are specific to the resources and limitations that this group operates within.

Study Aim and Objectives

The current study aimed to explore the subjective experiences of New Zealand patients (Māori and non-Māori), patients' family/whānau members, and HCPs (surgeons and nurses) when bad news was given to patients regarding a cancer diagnosis while accessing surgical services at Palmerston North Hospital. By hearing the voices of all parties involved, this study intends to gain a balanced perspective on the breaking bad news process and compare the experiences of the different parties involved. To achieve this, the current study had the following objectives:

1. Explore patients' and their family/whānau members' experiences of receiving, and HCPs' experiences of delivering, bad news about cancer within MDHB surgical departments.
2. Directly compare the various perspectives of those involved in delivering and receiving bad news within a single patient's case.
3. Make practical recommendations from the findings for the improvement of delivering bad news within the MDHB surgical departments.

Theoretical Underpinnings

Taking a qualitative approach. Approaching research from a qualitative standpoint involves exploring the meaning that individuals ascribe to a phenomenon (Willig & Stainton-Rogers, 2017). The qualitative researcher attends to the "quality and texture of experience" (Willig, 2013, p. 8), with great interest in how people make sense of the world and its associated phenomena, as uniquely experienced by them. This is in contrast to the ambitions of positivist researchers, who aim to make objective statements about a phenomenon, its causes and effects, or what is 'true' about it (Larkin & Thompson, 2012). Engaging with people's meaning-making is the channel through which the qualitative researcher gains deeper insights about an object or event of significance to people (Willig & Stainton-Rogers, 2017).

Within healthcare research, qualitative approaches have gained greater recognition over time as a means to highlight important topics of enquiry that are relevant to healthcare consumers (Biggerstaff & Thompson, 2008). While there is no doubt that there is value in focusing on quantifiable variables within healthcare (e.g., disease-rates), qualitative approaches have become an appropriate mode of enquiry when asking questions about the meaning a 'disease' holds to a patient within their life context. The current study concerns the meaning that patients, family members and HCPs make of their experience of receiving or delivering bad news about cancer, making a qualitative approach the appropriate match for the aims of the study.

Interpretative phenomenological analysis. Interpretative phenomenological analysis (IPA) is underpinned by a theoretical framework that aligns with a qualitative approach. In IPA, people's subjective meaning-making is of central importance, with the IPA researcher making no attempt at objective claims about the world (Smith & Osborn, 2008). IPA is committed to examining the meaning people make of significant life events to understand their personal lived experience (Eatough & Smith, 2017; Smith, Flowers, & Larkin, 2009). In this study, the event of significance is the process of receiving, or delivering, bad news about cancer.

IPA has a dual epistemological basis: phenomenology, which concerns the theory of experience, and hermeneutics, which concerns the theory of the interpretation of a given experience (Smith & Eatough, 2012). IPA is phenomenological in that it concerns the study of experiences that become significant to people in their everyday flow of life. Many experiences pass by without conscious awareness in a 'taken-for-granted' fashion; however, when an event occurs that is important to an individual, such as being told of a cancer diagnosis, they attend to the experience for the meaning it holds to them (Smith et al., 2009). This meaning is inextricably linked to the life context in which they are immersed, and thus the experience of an event is always in relation to that context. This aspect of phenomenology was described by the philosopher, Heidegger, who referred to it as *Dasein* (literally meaning 'there being'). The process of an individual explicitly reflecting on the significance an experience holds for them, as a 'person-in-context', is the act of being phenomenological (Larkin & Thompson, 2012; Smith et al., 2009).

Hermeneutics underpins the nature of interpretation in IPA, given interpretation is a necessary condition for the expression of the meaning of an experience (Smith et al., 2009). In IPA, the participant's interpretation of their experience is said to be first-order, while the researcher's interpretation of the participant's experience is second-order, as they are only afforded access to the participant's experience through what they openly share with the researcher. The researcher's attempt to make sense of the participant's sense-making when conducting an IPA enquiry has been coined the 'double hermeneutic', given the double layer of interpretation (Smith et al., 2009). In this way, the IPA researcher has a crucial role in the research process and outcome. The hermeneutic stance of the researcher when engaging in interpretation is both empathetic and critical, whereby an attempt is made to see the participant's experience 'through their eyes', while also asking questions and puzzling over ways the participant's experience can be understood (Smith & Eatough, 2012).

There is a dynamic interplay between the two epistemological foundations of IPA (Smith et al., 2009). IPA is phenomenological in the quest to get as close to the participant's experience as possible, while acknowledging that this is grounded in the reality of hermeneutics, meaning knowledge of an experience is only possible through a process of interpretation on behalf of both the participant and researcher (Smith et al., 2009). As such, it is said that a phenomenological and hermeneutic stance enables the researcher to become 'experience-near' (Eatough & Smith, 2017). The threads of this dual epistemology are dependent on each other, in that phenomenology allows there to be something to interpret, and the process of interpretation (i.e., hermeneutics) enables the nature of the phenomenon in question to come to light (Smith et al., 2009).

There is a third theoretical tenet that is influential in IPA: idiography. IPA is idiographic in the commitment to examining, in detail, participants' individual accounts of their experiences (Smith et al., 2009). In attending to the specifics of an individual's account, IPA places participants' accounts within their life context. This relates to the concept of *Dasein* by acknowledging that all experiences are given meaning in relation to the context in which they occurred (Smith et al., 2009). When general statements are made within an IPA enquiry, the idiographic commitment is sustained by grounding these statements in specific examples of cases (Eatough & Smith, 2017). In practice, this relates to the use of examples and direct quotes to retain the 'texture' of each participant's experience.

Reasons for choosing IPA. A phenomenological and hermeneutic stance is appropriate for the aim of the current study as it enables in-depth exploration of the meaning patients, family members, and HCPs ascribe to the experience of receiving and delivering bad news about cancer.

Receiving bad news is understood as a process that occurs over time, with significant aspects before, during, and after the news is communicated to the patient, with the entirety of the process important to examine in this current study. IPA is ideally placed to explore the meaning people make of processes, rather than limiting the analysis to outcomes. There are no predetermined hypotheses in IPA (Smith & Osborn, 2008), so the current investigation will not be constrained by these preconceptions and will, instead, encourage novel insights to come to the fore.

The commitment in IPA to idiography means that the participants' experiences are placed within their personal contexts, providing a specific understanding of what it is like for each individual to receive bad news about cancer within the surgical departments of Palmerston North Hospital. This idiographic approach also means that interpretations across participants' accounts can be contextualised within specific participant experiences.

Researcher reflexivity. While the researcher facilitates access to the meaning of a participant's experiences in IPA, this process is also complicated by the researcher's biases, assumptions, and personal lived experiences (Smith & Eatough, 2012). Thus, the researcher is required to engage in a process of reflexivity before, and during, the research process to bring into awareness any preconceptions. This process is termed 'bracketing' (Smith et al., 2009).

Upon beginning this study, I reflected on the possible role my age, gender, ethnicity, and academic study could have on the data collection and interpretation processes. I am a young female of New Zealand European ethnicity, born in South Africa, with the privilege of engaging in doctoral-level study in Clinical Psychology. I recognised that these variables could influence the type or depth of information participants discussed with me. It may be that participants of a different generation, gender, or ethnicity may have found it more challenging to relate to me and this could have impacted how open they were about this sensitive topic. I could have also been viewed as an 'expert' due to my level of academic study and participants could have made assumptions about what I might want to, or already, know. In an attempt to address these aspects, I aimed to create rapport with all participants early on in the interview process and explicitly stated that I was there to hear their story in the way they wanted to share it.

I considered my ‘outsider’ position in regards to the topic and locality of this study. I had not directly experienced receiving bad news about cancer myself, and while I had been informed of cancer affecting my wider family, this had not been within the New Zealand healthcare system. Additionally, I had no connection to, or experience with, MDHB or Palmerston North Hospital, nor the communities that they serve. Therefore, I interpreted the data without the influence of direct, personal experience.

I also bracketed the anecdotal evidence I had about HCPs and the New Zealand healthcare system. I have been brought up in a family with a parent and siblings working as HCPs, meaning that I entered this project with subjective knowledge of some of the challenges HCPs can face. Additionally, through discussions with those working in healthcare, and those who had accessed healthcare services, I had heard that surgeons were often criticised for their interpersonal skills. To bracket these pre-understandings, I actively worked to keep an open mind during data collection and interpretation.

In addition to the steps outlined above to bracket my assumptions and biases, I kept a diary of reflections and impressions following each interview and reviewed this when beginning interpreting the data. I also kept notes during the interpretation phase in an attempt to set aside ideas that arose from each participant’s interview. The intention was that this process would lessen the influence one interview’s interpretation had on subsequent interpretations, recognising the individuality of each participant’s experience and upholding IPA’s commitment to idiography (Smith et al., 2009).

Consumer Involvement

There has been a movement in healthcare to recognise the importance of involving the consumer in research, policy and service development (Boote, Telford, & Cooper, 2002). The participation of consumers demonstrates a shift away from paternalistic models of healthcare (where the doctor or researcher is assumed as the ‘expert’), to collaboration and partnership (Hubbard, Kidd, Donaghy, McDonald, & Kearney, 2007). Epistemologically, consumer involvement takes the stance that knowledge is created by hearing the perspectives of those who have direct experience. In this way, including consumers in research aligns with the epistemological foundations of IPA.

A review of the literature demonstrated that those affected by cancer have been included in research as advocates, advisors, reviewers, strategists and participatory researchers (Hubbard et al., 2007), with levels of involvement ranging from consultation to research fully controlled by the consumer (Boote et al., 2002). The benefit of consumer involvement in research is that research questions can target important issues for those the research may affect, facilitating more targeted use of resources. Consumers can also enable access to marginalised groups and support the dissemination of research information among other consumers (Boote et al., 2002).

Drawing on the epistemological, ethical and practical arguments for consumer involvement, the current study included a consumer advisory group as part of the study development, implementation, and outcome (see Otaki advisory group). The genesis of the project was within the 2014 Otaki hui, which included members from the local iwi living in the Otaki community who were consumers, or whānau of consumers, of MDHB cancer care. The generosity of the many Māori community members from Otaki (henceforth referred to as Otaki whānau) was invaluable, as they shared their knowledge and experiences at the hui to highlight the need for the current study. To honour the roots of the project, the advisory group was made up of Otaki whānau with experience in receiving bad news about cancer directly or as a whānau member. Some members of the advisory group also came with experience working in cancer care in the Otaki community.

There were three additional reasons for the nature of this study's advisory group. Firstly, the advisory group members provided an important 'insider perspective' that I did not hold, being non-Māori, and not having experience with, or connection to, the Otaki community. As such, the lived experiences of the advisory group members (with regards to MDHB cancer care and the needs of the community) was of great value to me and the study, as I wanted the project aims to be relevant to their needs. Secondly, it was important that the voices of Otaki whānau, who were the beginnings of the project, were included in the study's participant group. The advisory group provided guidance on appropriate ways to engage with Otaki whānau and helped facilitate access to potential participants through their networks. Thirdly, feedback from the advisory group on the study's findings enabled collaboration with those who had knowledge of how the idea for the project started.

The process of engagement and consultation with the advisory group will be detailed in the Method section.

Ethical and Cultural Considerations

The current study received ethical approval from the Health and Disability Ethics Committee (reference number: 16/NTB/164) and the MDHB Māori Review of Research panel. All participants were fully informed prior to consenting to participate, through the distribution of a detailed information sheet (see Appendix G) and opportunities to ask questions. An 0800 number, which participants could call free of charge, was provided for participants if they had any questions about the research. Participants were able to withdraw their consent up to one month after receiving their transcript to review. It was emphasised to patients and their family/whānau that not participating in the study or withdrawing at any time had no bearing on the current or future healthcare they received from MDHB. No health information was shared with the researcher at any stage, other than that which participants chose to disclose. Participants' identities were protected by assigning pseudonyms at the transcription phase, along with identifying information being removed from the interview transcripts. All data was, and continues to be, securely stored on a password-protected computer that only the primary researcher has access to, and the data will be destroyed after 10 years.

The safety of the participants and myself, as the researcher, was carefully considered in this study. When interviews were conducted in participants' homes, the location of the interview, and the start and expected finish times, were shared with my primary supervisor. I had a cell phone on me at all times, and contact was made when the interview finished. In regards to participant safety and comfort, participants were invited to bring along a support person(s) to the interviews (known to them or independent; see Appendix H), and a list of helpful services were made available to participants in the event that discussing delivering or receiving bad news caused distress (see Appendix G).

Cultural considerations are important when conducting research within New Zealand's unique bicultural context, acknowledging both Māori and non-Māori. When engaging with participants, an opportunity was made for *whakawhanaungatanga* (establishing relationships), *karakia* (prayer) and the sharing of *kai* (food). The establishment of the advisory group and cultural supervision through Massey University meant Māori were involved, and consulted with, throughout the project. A *koha* (offering), in the form of a supermarket voucher, was offered to all participants for taking the time to share their experiences. Presentations of the findings were also offered to interested community and professional groups for collaborative discussion and feedback, as a way to acknowledge their valuable contribution to the study.

Method

Otaki advisory group. The process of establishing the advisory group began with consultation with both my research and Māori cultural supervisors on the best way to initiate contact with Otaki whānau who attended the hui and knew how the project idea started. I was not present at the 2014 hui and so was unknown to the leaders and Otaki whānau who participated. My primary supervisor facilitated email contact with one of the Māori community leaders and a hui was organised in Otaki. My primary supervisor and I attended, along with several Otaki whānau who had been directly affected by cancer and/or involved in health and cancer care in the Otaki community. This hui was held during the early stages of project development and the hope was to form connections and establish how the goals of the study could align with the needs of the community. There was interest from the group in the study and a productive discussion was had about ways the research project could include Otaki whānau in the participant group of patients and family/whānau members served by MDHB surgical services.

Following this, email contact and a number of face-to-face meetings were had with the main representative for the Otaki whānau in the project. It was identified that there needed to be a formalised process of consultation if the voice of the Māori community was to be meaningfully included in the project. On the guidance of my University cultural advisors, the idea of an advisory group was suggested and an advisory group of four Māori community members from Otaki was established. The advisory group and I met in person to discuss the project, which resulted in several key changes suggested to enable Otaki whānau to be better included in the study sample. I then facilitated a process of negotiation between my University-based supervisors (research and cultural) and the advisory group until an agreement was reached on changes to make to the study. These negotiations would have ideally been in person; however, due to geographical distance and busy schedules, these negotiations were carried out over a period of time and predominantly via email correspondence.

The chance to *kōrero* (speak) in person came with an invitation to present the updated research proposal for wider community feedback at a hui designed to be a follow-up to the original 2014 Otaki hui. A *mihi whakatau* (welcome) process was followed, during which attendees shared information about who they were and their background. Following the mihi whakatau process was important to acknowledge and respect differences amongst those in the room before a working relationship could be established. This was crucial to the process of engagement and the outcome of the hui was that discussions could now begin about recruiting Otaki whānau as part of the wider participant group in the study.

In total, the process of engagement with Otaki whānau spanned over a year and only represented the beginning of my involvement with the Otaki community. Throughout the study, contact was maintained to update the advisory group on research progress and share the study findings for feedback. A summary of the research findings was sent to advisory group members (see Appendix I) and a presentation to the Otaki community was offered.

Semi-structured interviews. Semi-structured interviews were used to gather data on how participants made sense of their experiences of receiving, or delivering, bad news. Semi-structured interviews are considered the most appropriate method of data collection in an IPA enquiry, due to the flexibility in what can be covered in the interview (Smith & Osborn, 2008). When using a semi-structured interview, participants are free to share aspects pertinent to their experience that may be novel to the area, and interviewers can probe areas of interest. In this way, semi-structured interviews facilitate rich and detailed accounts of participants' experiences (Smith & Osborn, 2008). The flexible nature of a semi-structured interview can also help rapport between interviewer and participant to be established, as space is given for participants to tell their story in the way they want to express it (Larkin & Thompson, 2012; Smith et al., 2009).

Participant criteria. Participants for the semi-structured interviews included patients, patients' family/whānau members, surgeons, and nurses. Table 6 outlines the inclusion criteria for each participant group.

Table 6

Participant Inclusion Criteria for Semi-structured Interviews

Participant	**Inclusion Criteria**
Patient	• Adult (18 years and older). • Having been through a surgical treatment process for cancer that involved receiving bad news one or more times during this journey. This may include being informed of a cancer diagnosis, prognosis, the need for further treatment, or a transition to palliative care. • The surgical procedure was conducted at Palmerston North Hospital. • At the follow-up stage of treatment (approximately 3 months or more post-treatment) so were more likely to be in a position to reflect on their experiences of receiving bad news. • Eligible regardless of the outcome of their cancer treatment (i.e. successful or unsuccessful).
Family/whānau member	• Adult (18 years and older). • Present at one or more occasions when their loved one (a patient participating in the study) was given bad news. • Anyone close to the patient, not necessarily a blood relative.
Healthcare professional	• Surgical consultant or nurse involved in delivering bad news to patients with cancer, or specifically to an interviewed patient (as part of a 'linked case'; see description below in *Data collection procedure*). • Employed by MidCentral District Health Board.

Participant recruitment. The recruitment of patients and family/whānau members began by establishing interest from hospital- and community-based healthcare workers in being involved in the recruiting process. To preserve patient confidentiality prior to the patient's agreement to be part of the study, hospital staff and cancer community workers took responsibility for identifying patients and their family/whānau members who: met the inclusion criteria; would not be unduly burdened by participating; and would provide a range of perspectives on the process of receiving bad news. These potential participants were provided with a study information sheet (see Appendix G). Identifying information of patients and their family/whānau remained unknown to the researcher until they chose to make contact with the primary researcher via the contact details provided on the information sheet, expressing their interest in participating (see Appendix J).

Recruitment of health professionals was two-fold. Firstly, information about the study was emailed to the HCPs that patients had consented to being contacted as part of a ‘linked case’ (HCPs had no obligation to accept this invitation). Secondly, information about the study was distributed to HCPs in the involved surgical departments via email by the hospital staff assisting with recruitment to gain a wider inclusion of HCPs in the study. HCPs who were interested in participating made contact with the primary researcher.

Participant characteristics. The participants were a purposive sample of 10 patients, 6 family/whānau members, 5 surgeons and 6 nurses. The rationale for this sample size and configuration was two-fold. Firstly, the sample size needed to be small enough to enable detailed examination of each case as part of the idiographic mode of enquiry in IPA (Smith & Osborn, 2008), but also large enough so that each group (i.e., patients, family/whānau, surgeons, and nurses) could be analysed as a stand-alone group. Smith and Osborn (2008) suggested five to six participants (per group) is sufficient.

Secondly, the current study was designed to include family/whānau members’ perspectives, given the need for research involving this group, both within New Zealand and internationally. Patients were always the first point of contact so they could be given the autonomy to decide if they wanted their family/whānau included. Family/whānau could decline this invitation and patients could participate in the study regardless of their family/whānau participation. As family/whānau were always ‘linked’ to patients in an effort to develop linked cases, recruitment of patients continued until there was an adequate number of family/whānau members to form a stand-alone group.

Patients and their family/whānau members resided in a number of different locations across the area serviced by MDHB. There were three sets of patients and family/whānau living in Otaki, and one set from Levin, Foxton, and Pahiatua. These are all small communities whose inhabitants have to travel to Palmerston North for specialist appointments and cancer treatment. Of the remaining four patients who did not have family/whānau participating in the study, three were from Palmerston North and one was from Levin. To protect participant anonymity in a relatively small community of patients and employees of MDHB, participant characteristics are presented in Table 7 as amalgamated for each group of participants.

Table 7

Characteristics of Semi-structured Interview Participants

Participants	**Characteristic**	**Mean (range)**	**n**
Total			27
Patients			10
	Age	60.3 (33-80)	
	Sex		
	Male		8
	Female		2
	Ethnicity		
	NZ European		6
	Māori/European		2
	Māori		1
	African		1
	Cancer type		
	Prostate		4
	Bowel		4
	Breast		1
	Testicular		1
Family/whānau			6
	Age	56.2 (44-69) [4]	
	Sex		
	Male		1
	Female		5
	Ethnicity		
	NZ European		4
	Māori/European		1
	Māori		1
	Relationship to patient		
	Partner/spouse		4
	Child		1
	Other whānau member		1
Surgeons			5
	Age	50.6 (39-56)	
	Sex		
	Male		5
	Ethnicity		
	NZ European		4
	European		1
	Years as a consultant	(4-21)	
	Surgical speciality		
	Urology		3
	General surgery		1
	Obstetrics and gynaecology		1
Nurses			6

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[4] Mean and range calculated from the five family/whānau members that provided this information.

Age	50.8 (46-58)[5]	
Sex		
Female		6
Ethnicity		
NZ European		3
Māori/Pākehā		1
European		2
Years as a nurse	(23-41)	
Clinical role		
Clinical nurse specialist		4
Registered nurse		2

Data collection procedure. A location, date and time for a face-to-face semi-structured interview was arranged when participants contacted the researcher expressing their interest in participating. Patients and their family/whānau members all opted to be interviewed in their homes and all HCPs chose to be interviewed at their place of work. These interviews occurred four to eleven months after patients had their surgical intervention. Patients and family/whānau members were given the option of being interviewed separately or together. Four sets of patients and family/whānau chose to be interviewed together. Participants signed a consent form (see Appendix K) prior to starting the interview, once their questions had been answered. Guided by a semi-structured interview schedule (see Appendix L), the interviews went for 30-80 minutes and were audio-recorded.

Patients were given the option of consenting to be part of a ‘linked case’, where the experiences of the patient, their family/whānau and the HCPs who delivered the bad news to them, were gathered through interviews. This meant that all parties’ reflections on their experience were ‘linked’ to the same patient’s case of breaking bad news. Consenting to a linked case meant patients agreed to: (a) inform the researcher of the names of the HCPs (surgeons and nurses) who were involved in breaking bad news to them; (b) the researcher contacting the HCPs to see if they were interested in being interviewed about a patient’s specific case of delivering bad news (identifying information of the patient not given); (c) the HCPs who agreed to participate being informed of the patient’s name and the patient’s participation in the study; (d) the HCPs accessing a patient’s medical file (if needed) to recall details of their specific case; and (e) the researcher talking to the HCPs

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[5] Mean and range calculated from the five nurses that provided this information.

about the patient's specific case of breaking bad news (see Appendix G for the information sheet and Appendix K for the consent form). HCPs involved in a linked case were also encouraged to reflect on their experience of breaking bad news to cancer patients in general.

There were a number of important aspects to note about the option of having a linked case. Firstly, whether patients consented to having a linked case or not did not impact their eligibility to be interviewed as a participant in the study. Secondly, when HCPs were contacted about participating in the study as part of a linked case, they were able to decline the invitation to participate in that capacity. However, if the HCP wished to participate as a non-linked case (i.e., making reflections on breaking bad news to patients in general), they were still eligible to be interviewed if they met the inclusion criteria (see Table 6).

Seven out of the ten patients interviewed consented to have the HCPs involved in breaking bad news to them contacted as part of a linked case. Two patients could not form linked cases as they either had no family members present when they were told bad news or no family members that agreed to participate, and none of the HCPs involved in their care responded to the invitation to participate. The linked case network consisted of five different patient cases and is depicted in Figure 1 (all names used are pseudonyms). In instances where a surgeon or nurse was not part of the linked case, this was due to the patient not knowing the name or contact details of this HCP or the HCP not responding to the invitation to participate in a linked case. In the case of 'Anna', no family members were present when she received the news about her cancer diagnosis, and only her nurse ('Mariah') responded to the invitation to be interviewed as part of a linked case.

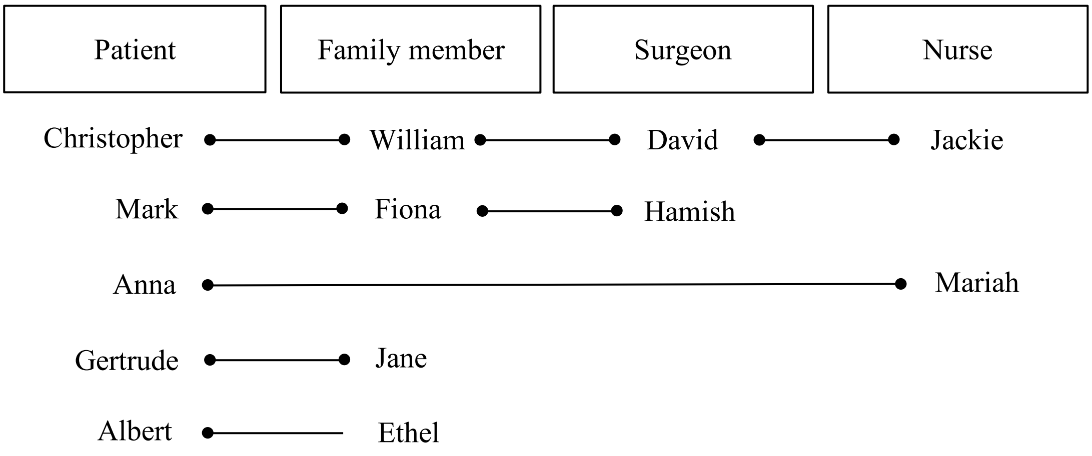

Figure 1. Linked Case Network. Note: All names used are pseudonyms to protect participant confidentiality.

The audio recordings of the semi-structured interviews were typed verbatim (see Appendix M for transcript notation). Transcripts were sent back to each participant for review, giving them an opportunity to change, omit, or add any information. When participants returned transcripts in which amendments were requested, these changes were made before the interpretation of the data began.

Data Analysis

The aim of the analysis was to identify patterns of meaning, or themes, in participants' lived experiences of the process of breaking bad news about cancer. While described sequentially below, the stages of interpreting the data were not linear. Rather, IPA is an iterative procedure, whereby the researcher moves back and forth between the stages of interpretation, examining the parts in context of the whole, and vice versa, in a process called the hermeneutic cycle (Smith et al., 2009). As such, the analyses cycled repeatedly between the phases of interpretation as it progressed towards the final interpretation presented in this thesis.

Congruent with the idiographic commitment of IPA (Smith et al., 2009), the process of interpretation began by focusing on one participant's account of their experience of receiving or delivering bad news at a time through to the stage of tentative theme development, before moving to the next participant's interview. The required close reading of the first participant's interview transcript began during the transcription phase, when the content and flow of the interview became familiar. The first participant's transcript was then read, and re-read, noting in detail aspects that seemed of importance to the participant and an interpretation of why this might be in the transcript margin, in a line-by-line fashion. While attempts were made to align with the meaning the participant gave to their experiences, there was also a critical interpretation of the data through questioning what could be underlying the participant's account they shared (Smith & Eatough, 2012). Differences, similarities, and contradictions were also noted throughout the participant's transcript, in an attempt to highlight the nuances of the meaning they gave to their experience (Smith & Osborn, 2008).

The initial codes made from the close reading of the first participant's transcript were integrated to develop tentative themes. These themes remained linked to the full transcript text, and thus kept in context, by providing relevant direct quotes alongside the themes. The themes from the first participant's transcript were organised into a framework of superordinate and subordinate themes. However, this structure was held flexibly to allow for new ways of organising themes to come to light when integrating multiple participants' experiences (Larkin & Thompson, 2012).

At this stage, the first participant transcript was put aside and the next participant transcript became the focus. All interviews from the patient group were analysed first, followed by the interviews with family/whānau members, surgeons, and nurses. Once all 27 participant interviews were individually analysed, this marked the completion of first phase of data analysis (see Figure 2).

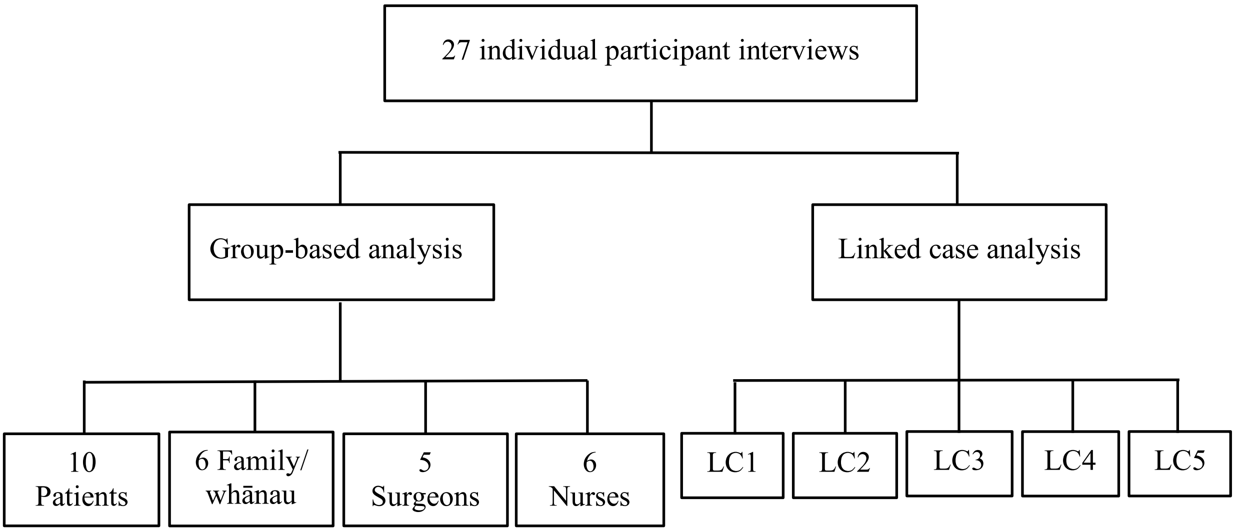

Figure 2. Process of Data Analysis and Groupings. LC= Linked case.

Following the completion of this first analytic phase, the quality of the interpretation of individual participant cases underwent a process of credibility checking (Larkin & Thompson, 2012). The primary, and one secondary, supervisor for the thesis each read and interpreted two transcripts from each of the four participant groups, providing handwritten initial codes. The initial coding was compared and discussed in a supervision meeting. In most cases, similar points of importance were identified; however, the comparison helped to better engage in the ‘critical hermeneutic’ and consider alternative interpretations of the meaning experiences may have held for participants.

The themes that arose from the individual participant analyses were then grouped in two ways to be compared and contrasted: by group and by linked case (see Figure 2). For the group-based analysis, superordinate and subordinate themes were developed across the 10 patient, 6 family member, 5 surgeon and 6 nurse interviews to represent the experiences of each group. The outcome of this group-based analysis will be presented in *Part One* of the next chapter. For the linked case-based analysis[6], all participants involved in 5 different patient cases of breaking bad news were looked at as a connected whole to directly compare their experiences of the process (see Figure 1 for the linked case network). The outcome of this interpretation will form *Part Two* of the next chapter.

Once the analysis was complete, a summary of the findings was sent to participants that had selected this option on the consent form and to interested parties within MDHB (see Appendix I).

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[6] Since designing and conducting this study, Larkin, Shaw, and Flowers (2019) have published a paper discussing the application of IPA to multiperspectival study designs and the potential this has to capture more complex experiences. This paper supports the current linked case design.

CHAPTER FIVE: FINDINGS AND DISCUSSION

This chapter presents the findings of the interpretation of participants' accounts of receiving and delivering bad news about cancer. It is written in two parts, representing the two ways the data were analysed: by group and by linked case.

Part One details the findings arising from the group-based analysis of patients', family/whānau members', surgeons', and nurses' experiences of the breaking bad news process. This attends to the first objective of the current study, which is to explore how patients and their family/whānau members experience receiving, and HCPs experience delivering, bad news about cancer within MidCentral District Health Board (MDHB) surgical departments. *Part One* is written in chapter format. As there are limited publications on breaking bad news within the New Zealand context and an underrepresentation of family members' perspectives on the bad news process internationally, future publications are planned based on these findings.

Part Two of this chapter attends to the second study objective, which is to directly compare the perspectives of the patient, their family/whānau, and HCPs involved in the same patient's case of delivering bad news to establish what was important for all those involved. A novel 'linked case' study design will be used to achieve this objective. This part of the chapter will be presented as the second manuscript in this thesis and will be written to the requirements of the target journal, while retaining a consistent referencing and formatting style to that of the overall thesis (see Appendix A for the statement of candidate contribution to the manuscript). The full reference for this manuscript is:

Matthews, T., Baken, D., & Ross, K. (2019). Single cases from multiple perspectives: A qualitative study comparing the experiences of patients, patients' family members, surgeons, and nurses when bad news is delivered about cancer. *Manuscript submitted to Journal of Psychosocial Oncology, Research, and Practice.*

A summary of the superordinate and subordinate themes in *Part One* and *Two* are provided below in Table 8.

Table 8

Summary of Superordinate and Subordinate Themes

Part of chapter	**Participant group(s)**	**Superordinate theme**	**Subordinate theme**
Part One: Group-based analysis	Patients	Preconceptions influence experience	Cancer means death Why me? Unmet expectations of care
		It's about person-person relationships	Valuing a personal connection See me as a person
		Concern for the carers	Bad news takes a toll on family Compassion for HCPs
		Support as a necessity	Needing support from multiple sources Coping matching needs and beliefs
		Bad news to survivorship influences your perspective	Greater appreciation for life Change in priorities
	Family/ whānau members	Guardian to the vulnerable patient	Being a patient protector Advocating for the patient
		Prioritising the patient	All attention on the patient Supporting patient autonomy
		Susceptible to being impacted	Supporters require support too Matching support to individual needs
	Healthcare professionals (surgeons and nurses)	No situation the same	Navigating variability and unpredictability The art of the tailored delivery
		No standard delivery approach	Delivery style reflects the deliverer Experience as the teacher
		Organisational variables constrain care	Time as a scarce resource Limitations of an unsuitable environment Workload demands erode empathy
		Bad news as a team-based task	Doctor as deliverer, nurse as supporter Family as a resource
		Psychological mindedness in a medical exchange	Reducing the emotional burden Valuing providing ongoing emotional care

		The personal toll of a professional task	HCPs as human too Coping to enable longevity
Part Two: Linked case analysis [Manuscript two]	Patients, family/ whānau members, surgeons, and nurses	Accurately perceiving and responding to needs	Noticing and meeting emotional needs Reading different informational needs
		Carers fulfilling necessary roles	HCPs as providers of connection and information Caregivers as able and willing to meet needs

HCP= Healthcare professional

CHAPTER FIVE: FINDINGS AND DISCUSSION

Part One:

The Experiences of Patients, Patients' Family/Whānau Members and Healthcare Professionals when Bad News is Broken about Cancer: A Group-Based Analysis

This part of the chapter is organised based on the four different groups involved in the breaking bad news process (i.e., patients, family/whānau members, surgeons, and nurses) that were interviewed in the current study. The findings from the interviews with patients and family members will be written separately, as they presented two different perspectives on the process of receiving bad news. However, while analysing the surgeons' and nurses' interviews as two separate groups, it became apparent that there was consistency in the themes arising from their accounts. As such, surgeons' and nurses' perspectives will be presented under the same theme headings. It will be noted from which profession (i.e., surgeon or nurse) and specific participant an aspect of a theme or direct quote originated. When referring to surgeons and nurses collectively, the term 'healthcare professionals' (HCPs) will be used.

The interpretation of patients' accounts will be described first, followed by family/whānau members, and finally, HCPs. The findings from each of these groups will be presented as a series of superordinate and subordinate themes (see Table 8), supported by illustrative direct quotes from participants. A discussion will be provided alongside the themes to locate the findings in relation to the existing literature.

Patients

Five superordinate themes were identified when interpreting the way patients made sense of their bad news experiences. These were labelled 'preconceptions influence experience', 'it's about person-person relationships', 'concern for the carers', 'support as a necessity', and 'bad news to survivorship influences your perspective'. Each of these superordinate themes, and corresponding subordinate themes, will be outlined below.

Preconceptions Influence Experience

Patients spoke about their experiences of receiving bad news in relation to their beliefs, understandings, and prior experiences, collectively labelled as their ‘preconceptions’. Patients had preconceptions about the meaning of cancer (‘cancer means death’), who was susceptible to getting cancer (‘why me?’), and their expectations of HCPs and the healthcare system (‘unmet expectations of care’).

Cancer means death. A powerful and common preconception referenced by patients was that cancer meant death. For Albert, John, and Mark, their reactions to being told they had cancer were influenced by their diagnosis bringing their mortality into close view. While it took Albert some time for the reality of having a cancer diagnosis to sink in, he described that moment of realisation coinciding with an awareness that his death might be near:

> *And even, it would have taken a week or two weeks, but then I suddenly- I remember one day sitting on the couch all day and, geez I've never told anybody this. My Dad died at the start of the war and anyway I was sitting there and I felt so bloody awful. You know, so depressed that I'd got this and I remember crying and looking up and saying, "I'll see you soon Dad." It was hard (Albert).*

Equating cancer with death meant that, for Mark, the word itself was imbued with such fear and power that he would not utter it until he was told he was free of cancer. Mark recalled:

> *But the one thing, I couldn't say the word 'cancer' until I'd been given the all-clear. I didn't want to say that word. I was afraid of that word. And it wasn't until [surgeon] rung me on Wednesday at quarter past eight and he said, "look, we've got your results back and you're all clear." And I just broke down (Mark).*

The gravity of the threat to life posed by cancer was particularly evident when patients spoke about their treatment decision-making processes. Wayne, Christopher, and Mark were given the option of surgery or radiation therapy, and all, without hesitation, opted for surgery. Mark stated that his immediate reaction was: *"Yip, get it out, get it out now."* It is possible that surgery represented the complete removal of a foreign entity from their bodies that was understood as a threat to their life. Wayne's reference to his father's experience of suffering and death from cancer may have reinforced the link between cancer and death for him, which he used as the rationale for his treatment decision:

> *My father died of cancer probably 10-years-ago and he suffered quite badly and I just wanted to get rid of mine as quick as I could virtually. So that's why I went for the prostatectomy (Wayne).*

Previous qualitative literature from Iran (Abazari et al., 2016), Malta (Chircop & Scerri, 2017), South Africa (Maree et al., 2014), and United States of America (Schaepe, 2011) describes patients equating cancer with death, establishing this as a prominent discourse, internationally. It was evident that this was relevant for patients in the current study, impacting their emotional reactions to being told of their cancer diagnosis, the language they used, and their treatment decisions.

Why me? Patients' preconceptions about who they believed were likely to get cancer influenced their reactions to their diagnosis and their understanding of why it had happened to them. Wayne, Mike and Albert all commented on their assumption prior to their diagnosis that 'others' got cancer, not them. Albert described:

> *Mentally, and I don't know if everybody thinks this way or not, but mentally "it only happens to other people, it's not going to happen to you. It's just going to happen to other people." And then you suddenly get it and it is one hell of a shock to the system (Albert).*

For Anna and Mark, their search for reasons why they had been affected by cancer revealed their assumption that cancer only affected those who deliberately did not look after their health or had done something to deserve it; neither of which they identified with. When asked of their reactions to being diagnosed, Anna and Mark shared:

> *Yeah, definitely a big shock. I guess everyone along the whole process thought- including myself- thought it was going to be nothing… I'm a pretty healthy person, I eat really well, exercise and do all the right things (Anna).*
>
> *It even tested my faith in God because I'm a born-again Christian, that's my belief. I'm thinking, "why's this happening to me? I've done good things" (Mark).*

John, however, identified himself as belonging to a group of people he believed would get cancer based on his strong family history of the disease. As such, he had anticipated that he would have already had cancer, and thus, was not shocked when told his diagnosis. He explained his reaction:

> *But I wasn't devastated or anything at all because all my sisters died before they were sixty, but I've had a good go at it, I'm 73 (John).*

Literature indicates that patients can have varied reactions to receiving a cancer diagnosis (Fallowfield & Jenkins, 2004; Matthews et al., 2019). Examples of patients in the current study aligning or not aligning themselves with who they believe would get cancer suggested the role of patient's health beliefs in how they react to being told of a cancer diagnosis.

Unmet expectations of care. Patients spoke about times when their expectations of the care they would receive from HCPs and the healthcare system were met or not. The degree to which patients' expectations were met was important, as violations of these expectations were considered by some to be the most significant 'bad news' they experienced during their cancer journey.

As stated in the previous theme description, John did not experience receiving his diagnosis of cancer as 'bad news'. For him, the bad news during his cancer journey was when he was not given access to free personal care products as he expected, and the reaction of the hospital staff when he confronted them about this. He was left feeling discriminated against and this reinforced his previous experiences of institutional racism towards Māori. John explained:

> *It doesn't matter where you go in New Zealand ah you get, um how can I put this, you've got this thing on you that, "oh yes here we go, here's another dumb Māori coming in here." But as soon as you open your mouth, things change a bit and ah they expect you to sit down, shut up and say nothing. But as soon as you start opening your mouth, "oh shit, he's a bad guy this fella, you better watch out" (John).*

Anthony spoke about his surgical complication as the most significant ‘bad news’ moment in his cancer journey, representing a violation of his expectation that his surgeon would be an expert and not make mistakes. His experience reinforced previous times when he had been similarly disappointed with the healthcare he received:

> *Well I hoped things would be better- yeah right. You know, 'cos once again- it wasn't a misdiagnosis, they knew straight away what was wrong, but it was the surgery that was wrong. It shouldn't have opened up underneath there, shouldn't have been. You know, a competent surgeon should not have had that happen (Anthony).*

Similarly, Christopher also experienced an oversight by a doctor as ‘bad news’. He was turned away twice from a biopsy appointment, after three hours of driving time to attend each appointment, due to the doctor not having done the necessary pre-tests. This did not align with his expectation that he would be treated by a competent and experienced doctor:

> *And I actually blame the young chap doing it, he was an intern. The way he was talking, he didn't really know his stuff. I think he was pretty young, I think just out of medical school by his age, so he didn't know- he knew about the urine sample being affected, but the second time, he wasn't quite sure what of two antibiotics to give me and I felt he could have done that the first time I went up there. He wasn't that good at his job I don't think (Christopher).*

In his influential text on how to break bad news, Buckman (1992) identified that the ‘badness’ of any news hinges on a patient’s expectations for their health and longevity. While Buckman aptly identified patient expectations as a key factor, the current findings highlighted the role of expectations of care from HCPs and the healthcare system in defining what patients experience as ‘bad news’. As such, bad news can arise from someone’s actions or inactions, as demonstrated in the current study, as well as being told that their health and longevity will not be as they expected, as outlined by Buckman (1992).

Additionally, the influence of patients’ expectations on their experience of what constitutes ‘bad news’ speaks to its subjective nature (Fallowfield & Jenkins, 2004). John, Anthony, and Christopher demonstrated that it cannot be assumed that being told a diagnosis of cancer would be the most significant ‘bad news’ moment. The subjectivity of bad news is reflected in the lack of specific parameters within widely used definitions of bad news in the literature (e.g., Ptacek & Eberhardt, 1996). The current study findings support the continued use of a broad definition of bad news to encompass the wide spectrum of situations and circumstances that can be considered ‘bad news’ by patients.

Overall, the superordinate theme ‘preconceptions influence experience’ highlights that patients’ understandings of the meaning of ‘cancer’, who they saw as likely to be diagnosed with cancer, and the care they expected from HCPs and the healthcare system, provided the lens through which they made sense of their experiences. While some patients’ preconceptions were informed by the common discourse of cancer meaning death, others were individual, based on their personal health beliefs and expectations of care. In all instances, patients’ preconceptions informed how they reacted to the care they received, and when their preconceptions varied, so did their reactions. This finding suggests that HCPs understanding patients’ preconceptions may help HCPs to make sense of patients’ reactions.

It’s about Person-Person Relationships

Patients spoke about the interpersonal dynamics between themselves and their HCPs that were important for genuine relationships to form in their interactions. This included establishing a personal rapport with their HCPs (‘valuing a personal connection’) and feeling their HCPs saw them as people, rather than just another medical case (‘see me as a person’).

Valuing a personal connection. Achieving a personal connection between themselves and their HCPs was valued by patients when they reflected on their experience of receiving bad news. For Mark, John, and Albert, this rapport came from finding common ground with their HCPs by establishing shared beliefs, background, and humour. Albert explained the friendly nature of his relationship with his surgeon:

> *And certainly [surgeon], he's almost a friend now. I see him every time I go up there, you know. It's, "Albert, what are you doing here again?" You know, "ah come on" (laughs)(Albert).*

When it came to HCPs verbalising the bad news to patients, the manner in which this was delivered by HCPs was important for developing rapport at that difficult time. For Albert, Anthony and Mark, their HCP’s easy-going and personable manner was appreciated. The following dialogue between Albert and his partner, Ethel, exemplified this:

> *Albert: Not so much in what he said, but if you believe in auras, the aura that came off him-*
>
> *Ethel: It was his manner, his general manner is just, he's friendly, he's approachable. Tells you how it is. Calls a spade a spade.*
>
> *Albert: It is a spade, but it's got a golden handle (laughs).*

Gertrude’s account demonstrated that a HCP making an effort to form a personal connection with a patient can help to repair a HCP-patient relationship that might have previously been strained. The surgeon’s apology for misdiagnosing her prompted Gertrude to feel compassion towards him, repairing their relationship:

> *And anyway, I remember [doctor], he's quite a young guy, very nice. I like him- my daughters don't and um he comes in the second time I was in hospital and he comes round- peeps around the corner, "aw Gertrude, I am so sorry"*

> *he said. "I should have, I should have picked it up" he said. "But, I am just so sorry. As soon as I saw your name" he says, "I knew." So that was nice of him, I felt sorry for him actually 'cos they work so hard (Gertrude).*

The importance to patients of forming a personal connection with their HCPs found in the current study has been reported previously in the literature. Matthews et al.'s (2019) meta-synthesis identified that the HCP-patient relationship was key in preparing a patient for bad news about cancer and helping them cope with the on-going implications. For the patients in the current study, a personal relationship arose from HCPs establishing common ground with patients, engaging in a personable manner, and making efforts towards repairing strained relationships. In many ways, this was about HCPs demonstrating their human qualities. The current theme supports HCPs focusing on using interpersonal skills in the breaking bad news encounter that help build rapport and demonstrate their humanity.

See me as a person. Patients talked about wanting to feel recognised as people whose wellbeing was valued, and whose ill-health was taken seriously, during the exchanges they had with HCPs. The importance of this was demonstrated in instances when patients felt personally valued, and in instances when they did not.

One way in which patients felt undervalued was in regard to not receiving prompt treatment. This was particularly pertinent for Christopher who experienced a long waiting time for his surgery and understood this waiting period as directly resulting in the worsening of his cancer. Christopher explained:

> *It is alright if it is benign, it doesn't matter, but if you have malignant cancer, you should not have- no one should have to wait seven months for surgery when they are told they have malignant cancer. And every day I worried about that for seven months, I was worried sick about it, I was a nervous wreck, wondering all the time where it is spreading to. They told me it was the spreading kind so where- they didn't say where it was going. They told*

> *me it was malignant and it was spreading, so tell me where it is going? My lungs, my kidneys? (Christopher)*

The way Christopher spoke about his surgery wait time indicated that he took the delay as if a decision was made to de-prioritise him, making it understandable that he felt personally undervalued by it. While his wait time was likely influenced by demands on the healthcare system and limited resources, he experienced this as being personally de-valued within an interpersonal exchange between "*they*", his HCPs, and himself.

In the following extract, Michael demonstrated his understanding of his prompt surgery as influenced by the availability of resources, possibly due to the fact that he was a HCP himself and may have an understanding of how the healthcare system worked. However, he also referenced his surgeon's emotional reaction to him as a patient as influencing the promptness of his surgery, re-establishing a personal basis for his treatment wait time. Michael said:

> *The surgeon saw me on like a Tuesday and then on the Thursday, he took me to theatre for the operation. So, it was very, very quick...I was lucky [surgeon] at that time didn't have a big list and I guess he was just feeling a bit sad for me as well (Michael).*

Christopher and Michael provided examples of how patients could interpret their surgery wait times as being relevant to how valued they were by their HCPs and the level of empathy HCPs had for them, even if their wait times may have been entirely driven by resource availability.

In instances when patients felt like they were seen and valued as people, they spoke about feeling genuinely cared for as individuals and not regarded as merely another number or case. Anna articulated how important this was to her when describing the positive experience she had with the hospital staff during her cancer diagnosis and treatment:

> *I just- I feel like every single staff member I've dealt with genuinely cares about you and you are not just a number. I definitely do get the feeling that they want the best for you and they want you to get better and that helped heaps. Knowing that they are wanting the best for you (Anna).*

The importance to Anna of experiencing a sense of being cared for as an individual by HCPs is consistent with a number of previous qualitative studies (e.g., Blakely et al., 2017; Randall & Wearn, 2005; Thorne et al., 2010). The current finding, thus, supports patients feeling valued and cared for as individuals as a key consideration when bad news is delivered.

Overall, the superordinate theme 'the bad news encounter is about relationships' highlights that the interpersonal aspects between patients and their HCPs during the breaking bad news process were perceived as important. This involved patients forming a personal connection with their HCPs and feeling a sense of being recognised, valued, and prioritised as a person in the care they received. This finding suggests the value of HCPs prioritising the building of rapport with patients and impressing on them that their health and wellbeing is individually valued. While HCPs have a role to play in achieving this through utilising effective interpersonal skills, the impact of surgery wait times on a patient's sense of being personally valued (and the fact that building rapport can take time), points to the importance of having an adequately resourced healthcare system.

Concern for the Carers

Patients spoke about bad news not only having an impact on themselves, but also impacting those who were caring for them. They expressed concern for the effect that bad news had on their family/whānau ('bad news takes a toll of family') and the challenge of the breaking bad news process for HCPs ('compassion for HCPs').

Bad news takes a toll on family. Patients recognised that bad news impacted their family members who were present when this news was delivered. In the following two extracts, Wayne and Gertrude shared that their initial reactions to receiving their diagnosis of cancer were concern for the bearing this would have on their family members, rather than on themselves:

> *I was alright. I was just more worried about Patricia probably than anyone else (Wayne).*
>
> *I watched their faces, I watched their faces and especially [daughter] having gone through cancer with her own son and um I just said, "I'm sorry*

> *[daughter]", you know (becomes tearful) to put her through that again (Gertrude).*

The concern expressed for family members suggested that patients understood bad news as not solely impacting them as individuals, but the family members who are close to them and involved. This finding aligns with models of breaking bad news that include the involvement of family and the impact bad news has on them, as a key consideration (e.g., Laidsaar-Powell et al., 2018; Rabow & McPhee, 1999; Salem & Salem, 2013; Villagran et al., 2010).

Compassion for HCPs. When reflecting on their own experience, patients also commented on the burden breaking bad news must have on HCPs who deliver the news. For Mark, the frequency with which HCPs had to break bad news prompted his compassion for his surgeon. He explained:

> *They've got to tell you 'cos you've been diagnosed with it, someone has to tell you, somebody has to give the bad news. The way it was delivered to me, it was probably harder for them, thinking back now, it can't be easy for them 'cos they must do that every day... So as much as it was bad news for me, yeah, it must be hard for them (Mark).*

For Gertrude, her compassion for the HCPs who cared for her arose from recognising the demands of their role and how challenging that would be for any human being:

> *I mean, they are human beings like us, they work untold hours, you know, how can they fit all of that in their brain (gasp). It's mind-boggling (Gertrude).*

Concern for how challenging the role of the doctor can be, helped both Mark and Gertrude to reframe mistakes HCPs made during their care (e.g., misdiagnosis of symptoms) and prompted them to take a stance of compassion towards their HCPs. The recognition of the impact that breaking bad news can have on HCPs in terms of increased stress levels has previously been identified in the literature (Shaw, Brown, & Dunn, 2013); however, an increase in compassion as a result of patients acknowledging the challenge of this task for HCPs, has not been emphasised in previous qualitative findings.

Overall, the superordinate theme 'concern for the carers', highlights that patients in the current study were able to express their concern for others who were involved in the breaking bad news process, viewing family members and HCPs as equally vulnerable to the emotional burden of the bad news process. It was evident from patients' accounts that some were immediately concerned about their family members who were present when they were told of their diagnosis. However, when it came to concern and compassion for HCPs, it is unknown whether patients' successful cancer treatment or the passage of time between patients hearing the news and being interviewed for this study, helped facilitate this perspective. These contextual variables are important to consider in this finding.

Support as a necessity

The inherent difficulty of receiving bad news about cancer meant that a key part of patients' experiences was how they coped with this news. For all patients, receiving support from multiple sources was important, including emotional and practical support ('needing multiple sources of support'). However, what type of support was found to be most helpful for coping varied from patient to patient based on their needs and personally held beliefs ('coping matching needs and beliefs').

Needing multiple sources of support. All patients spoke about support being crucial, as receiving bad news was viewed as a heavy emotional load that no one should carry on their own. Albert and Michael both shared how important it was to have their partners present with them for support when they were told the news:

> *I can't stress enough the support you need when you are first told. It is probably the most important part of it. Helping you come to terms with it…and without her [gestures towards partner], I don't know what I'd do (Albert).*

> *Hm interesting. [Wife] was stronger than me. Normally I would have- it would have been the other way, but that day she was stronger than me. But I guess that was good because I was very weak at that moment. I needed somebody to be strong to support me (Michael).*

Bousquet et al.'s (2015) review of the literature reported that oncologists view family members as an important factor in patients coping with the emotionality of the news. While patients in the current study concurred with this, they also spoke about appreciating the support from others as well, forming a network of support.

Albert, Anthony, Anna and John mentioned benefitting from having support from community cancer support services that they could draw on alongside family/whānau based supports. Anna and Anthony explained how they used these services:

> *So, it was a few weeks after diagnosis I ended up emailing [community cancer support service] and asked, "what services do you offer?" And [cancer support worker] ended up ringing me asking me to come in for a meeting and we chatted. He is just another support person I guess, any questions, I can ask him. I haven't really used him a lot because the breast nurse answers all my questions, but it's good to know another person's there, I guess" (Anna).*

> *Somehow, I got to know [cancer support worker] and ah I asked and he said he was an advocate for people with cancer you know and "can he help?" "Certainly you can. Come to one or two meetings with me and take some notes." You know, because I live on my own, no family around me so yeah, it was good having someone like that (Anthony).*

Mark and Wayne noted that practical support from their employers to accommodate their need for time off and ongoing financial support helped to significantly reduce their stress during their cancer journey. Mark said:

> *And my boss and his wife have been really good because I was like off for 10 weeks and they just said, "look, we will see you when we see you. Just get well"... So that took a lot of stress off things. Being in the [emergency service], financial wise, there was money coming in through there that I wasn't expecting (Mark).*

International literature indicates that social support has an important role in cancer patients' health-related quality of life (Arora, 2007; Filazoglu & Griva, 2008; Lim & Zebrack, 2008). In the current study, the combined effect of multiple sources of support (e.g., family/whānau members, community cancer support services, and employers) helped patients feel cared for and able to better cope with the challenges of receiving bad news. This was consistent with Matthews et al.'s (2019) review of the literature that reported patients need support from several places when they have received bad news. As such, the current study findings and past literature indicate that the onus is not exclusively on family members to be the providers of support to the patient and that patients can benefit from access to multiple sources of support.

Coping matching needs and beliefs. Patients spoke about what helped them to cope when receiving bad news, and this varied across the patient group. Some patients identified the importance of receiving lots of information to support them to cope with being told of their cancer diagnosis. This was the case for Anna, who demonstrated this by contrasting her negative experience with her GP who initially told her of her diagnosis without providing information (extract 1), and the positive experience she had with a nurse at the breast cancer specific clinic who gave her the information she desired (extract 2). Anna explained:

> *I tried to ask [GP] a couple of questions, like what was the cancer even called, what was the extent of it. He immediately sort of said, "look, I really don't know. I don't know the details of it… There was no guidance as to what I should then do – nothing… No pamphlet, no info sheet, no written information of any sort, no phone number for anyone… I just thought, "I*

> *need more information. I need more. I need to know exactly what I'm dealing with here, right now (Anna; extract 1).*

> *What [nurse] did for us that afternoon I was so thankful for. I actually took her a gift basket the following week and a card saying, "you probably don't even remember me you must have so many patients, but what you did for us that afternoon, telling me exactly what I was dealing with- what I was going to be up against within the next few months, it just helped me so much." It meant everything (Anna; extract 2).*

By contrast, some patients spoke about being provided with information at the time of being diagnosed as not being the coping strategy that suited them. This was the case for Albert, who shared:

> *I am sure they explained it properly, I was just wasn't ready for it (Albert).*

Similarly, Anthony had been given written information about his chemotherapy treatment when it commenced, but chose not to read all of it as this elicited a sense of fear. Anthony explained:

> *You know, even this [chemotherapy information]. I've read some of the side effects but not all of them, I mean, it's scary! (Anthony)*

Information-seeking as a coping strategy has been recognised in the cancer literature. In a review article, van der Molen (1999) reported that acquiring information helped a patient to reduce their sense of vulnerability, possibly by reducing the confusion that might arise from getting a cancer diagnosis and treatment. While this reflected the coping style of some patients in the current study (e.g., Anna), this was not the coping strategy that was helpful for every patient (e.g., Anthony).

Another example of the variation in patients' coping styles was how important it was for some patients to connect to their faith or spirituality when coping with their bad news. This was particularly significant for patients who identified as having a faith, such as Michael, Gertrude and Mark, but was not mentioned by patients for whom this was not identified as important. Michael and Gertrude explained:

> *That's how I felt with the spiritual care because I just thought, "wow, there is someone out there who is actually looking at me and maybe He is just trying to see how strong I can be, but actually I am okay and I am going to be alright." So, you get strength from those kinds of discussions (Michael).*
>
> *Well my deep faith in God has really got me through this, really, it's all thanks to Him that I'm sitting here. So that's really the base-basis of how I got through all this (Gertrude).*

The role of spirituality in coping with cancer has been identified in studies from India (Martis & Westhues, 2015) and Iran (Abazari et al., 2016). These studies suggest the importance of HCPs recognising when faith is meaningful to patients and can be included in the process of delivering, and helping the patient make sense of, bad news. This was particularly significant for Mark, who, on finding out his surgeon had a similar faith to him, stated: *"'God's got this sorted, I've got the best doctor', you know."*

A person's spirituality has been described as one of the four cornerstones of holistic wellbeing in the model Te Whare Tapa Whā, which has been developed in New Zealand from a Māori worldview (Durie, 2001). The importance of spirituality for some patients in the current study suggests the potential relevance of applying a holistic model of healthcare in the context of breaking bad news to prompt HCPs to explore whether spirituality is significant for the patient and how this could be used to help them cope.

This subordinate theme illustrates that patients' coping styles can vary between individuals, demonstrated through the examples of the quantity of information desired and attending to spirituality. This suggests the importance of HCPs getting to know what helps a particular patient to cope and tailoring their support accordingly.

Overall, the superordinate theme 'support as a necessity' highlights that patients require support to cope with the difficulty of receiving bad news. Patients spoke about benefiting from receiving support from multiple sources and in a way that suits their individual coping styles. This finding suggests the need for patients to be supported in connecting with a broad support network and for HCPs to assess patient's individual coping styles in order for tailored support to be delivered.

Bad News to Survivorship Influences your Perspective

At the time of the interviews, all patients had been told that their cancer treatment had been successful or were in the final stages of completing treatment with a favourable prognosis. Patients made sense of this as having survived a close brush with death, which prompted a renewed perspective on life ('greater appreciation for life'). Patients also spoke about how their lives had changed going forward ('change in priorities').

Greater appreciation for life. Patients expressed an increased appreciation for life, having experienced their mortality being brought into sharp focus by their cancer diagnosis. Albert and Mark described their renewed perspective following the successful treatment of their cancer:

> *So, look around you and see what's happening out there, you know, enjoy seeing the birds and things… Ah yeah, you appreciate more than you'd believe. You remember things that you had forgotten, it's just looking for it. You know, when you get that close to death, you've got to do something. And it was close (Albert).*

> *Yeah, because I probably haven't put us first, but having cancer and a wakeup call that "this could have killed you." Not now, but if it was undetected, it could have down the track and it would be worse off. Yeah being home by myself while Fiona was at work and the time off work and thinking, "hm gee, you know, somethings need to change because you have been given a second chance or a wake-up call that yip, life is short (Mark).*

For both Mark and Albert, their newfound perspective was a positive outcome of the difficult experiences they went through, a 'silver lining'. This phenomenon has been labelled in the literature as post-traumatic growth (PTG) and studied in the context of cancer survivorship (e.g., Park, Chmielewski, & Blank, 2010). A qualitative study using group interviews found that PTG for cancer survivors took the form of positive improvements in their relationships, their perception of life and themselves, and spirituality (Connerty & Knott, 2013). The current study lends further support to the potential for PTG from cancer survivorship.

Change in priorities. Patients spoke about being motivated to make practical changes in their lives as a result of surviving cancer. For Mark, his cancer caused him to reassess what was important to him and to consider prioritising family over work commitments. Mark explained:

> *So, it's just those things and spending more time with the grandkids and going to their sports and trying to not get caught up in too many things. Although I'm a [position of responsibility] and there are certain roles I've got to do and I'm thinking, "ah do I just take a back seat on some of those?" And yeah, we've got a [major work event] coming up in a couple of years and I am thinking, "I might hang in for that." But it just puts a refocus on "what are we doing? What's important?" (Mark)*

Michael spoke about how his personal experience with cancer changed how he provided care to his patients in his role as a HCP. This took the form of listening more to patients (extract 1) and ensuring every patient had a support person with them (extract 2):

> *Um I think the most important thing is- and this is what has affected me now, I take my time to listen to the patient. I just want to hear what they want me to do. I tell them what I do and what I can do and then I ask them if they are happy with my suggestions. "Can I go ahead to do this, can I go ahead and do that?" Because that is how things worked for me (Michael; extract 1).*
>
> *You have to think of the patient, "how much support have they got? Who's there with them?" You know. And it's only until you've been in that kind of situation, that's when you realise- because I've been there myself, this is how now I realise actually that's very important. There should be- the people should always make sure that someone is there (Michael; extract 2)*

Mark and Michael's accounts demonstrated that the experience of receiving bad news about cancer and subsequently surviving can have an ongoing effect on patients' lives, whether this is personally or professionally. This finding suggests that patients' experiences of receiving bad news were not contained to the diagnosis and treatment of their cancer, but extended to the changes they made in their lives as a result. This further develops the notion that breaking bad news is a process over time (Matthews et al., 2019) to include the long-term and ongoing implications beyond successful cancer treatment.

Overall, the superordinate theme 'bad news to survivorship influences your perspective' highlights that patients consider the long-term implications of receiving bad news as part of the way they reflect on their overall experience of the bad news process. For the patients in the current study, this included the ongoing positive shifts in their perspective on life and priorities as a result of being diagnosed with cancer and having had successful treatment. This is an important contextualising variable to consider for the study as a whole and highlights the lens through which patients reflected on their experiences.

Summary

Five superordinate themes were identified when interpreting the way patients made sense of their bad news experiences. The first theme, 'preconceptions influence experience', established the role of patients' prior understanding of the meaning of cancer, who is susceptible to the disease, and the care they expect from HCPs in their reactions to receiving bad news. This was informed by widely utilised discourses of cancer and patients' personal histories and experiences. Identifying the preconceptions that patients bring to the encounter had the potential of offering HCPs a greater understanding of patients' reactions to being told health-related news and what they considered to constitute 'bad news'.

The second theme, 'it's about person-person relationships', highlighted the importance of an interpersonal relationship between patients and HCPs in which a personal connection is formed and patients feel a sense of being valued and prioritised. This pointed to HCPs utilising effective interpersonal skills to build rapport with patients, healthcare organisations enabling HCPs to have time to develop HCP-patient relationships, and the healthcare system being adequately resourced so patients can receive prompt treatment.

The third theme, ‘concern for the carers’, demonstrated that patients acknowledge the immediate impact receiving bad news can have on their family members and the burden on HCPs of having to carry out this part of their job. This suggested that patients can extend their concern and compassion to others involved in the process of them receiving bad news, recognising that breaking bad news can be a challenge for everyone.

The fourth theme, ‘support as a necessity’, illustrated the need for patients to receive support in order to cope with the challenges inherent in being told bad news about cancer. This was achieved through having a network of support that came from multiple sources (e.g., family/whānau, community cancer support services, and employers), as well as receiving support that aligned with each patient’s individual style of coping. This suggested the importance of connecting patients with support and exploring what would be helpful for each patient to meet their specific coping needs.

The fifth theme, ‘bad news to survivorship influences your perspective’, emphasised that the current sample of patients, who had, or were expecting, a successful outcome for treatment, experienced ongoing positive implications following the receiving of bad news. This took the form of developing a greater appreciation for life and re-assessing their priorities. Patients conceptualised these long-term implications as part of the bad news process. While this finding does not have direct implications for HCPs when they deliver bad news, it provides an important contextualising variable for the current study.

Taken as a whole, how patients spoke about their bad news experiences establishes that aspects that came before, during, and after receiving bad news are significant. The findings suggest that appreciating the complexity of receiving bad news requires understanding it as a process that is inextricably linked to a patient’s prior beliefs and experiences that they bring to the encounter; the interpersonal relationships they have with their HCPs, the concern and compassion they extend to others involved in the process, and their individual support needs during and after receiving bad news; and the ongoing psychosocial implications of their bad news experiences.

Family/Whānau Members

Three superordinate themes were identified when interpreting family/whānau members' accounts of being present when their loved one (i.e., the patient) received bad news. These were labelled 'guardian to the vulnerable patient', 'prioritising the patient', and 'susceptible to being impacted'. Each of these superordinate themes, and corresponding subordinate themes, will be outlined below.

Guardian to the Vulnerable Patient

Family members spoke about taking an active guardianship role in their support of the patient who had received bad news. Family members felt duty-bound to ensure no harm came to the patient ('being a patient protector') and that the patient was given access to the care and resources they deserved ('advocating for the patient').

Being a patient protector. Protecting their loved ones as they went through their cancer journey was spoken about by family members as an important and valued role. This responsibility was mentioned by Fiona, Misty-Blue, and Jane. In the following extracts, Misty-Blue described her protector role (extract 1) and what this meant for how she acted at the patient's (Lariko's) first appointment (extract 2):

> *His protector. Yeah, because he has told me a lot and he doesn't have his real whānau… And I think he relies on me a lot, yeah, so I see him as like a- try and just like protect him, yeah. I just wanted him to be like safe and yeah because he is a good person, yeah (Misty-Blue, extract 1).*
>
> *I just um 'cos when the doctor grabbed him, I said, "ah I'm coming (laughs), I'm coming into the room…I put myself there (laughs). I didn't even ask Lariko (Misty-Blue, extract 2).*

Fiona used the imagery of being a physical barrier between her husband, Mark, and the negativity of others to protect him from what she perceived was causing him harm. Fiona explained her role in the following exchange with Mark:

> *Fiona: As a protector. As a- I won't say so much support, but just to keep the negativeness away. Because I did get angry, I got really angry.*

> *Mark: Really angry.*
>
> *Fiona: Yeah, I did. Not so much over the fact that he had cancer, but it was my belief that because of Mark's personality, all this negativeness and people using you, I suppose, to a certain point?*
>
> *Mark: Over the years. Yip.*
>
> *Fiona: Yip, that that sort of what caused it. So, from then on, I was going to be the fence and they were going to have to get through me first, sort of thing.*

Family members taking on the role of ‘patient protector’ has been found when reviewing previous qualitative research (Matthews et al., 2019). Friedrichsen et al. (2001) reported that, in the context of incurable cancer, family members of Swedish patients tried to protect the patient by withholding information from them and only disclosing information when they felt the patient was ready, with the intention of minimising patient distress. While family members in the current study did not conceptualise protecting the patient as meaning non-disclosure, it suggests that, even in the context of a good prognosis, family members may perceive their loved ones to be vulnerable when they are given bad news and in need of protecting.

Advocating for the patient. Family members talked of the importance of advocating for their loved one, taking on the role of fighting on their behalf for better, or more prompt, treatment. Misty-Blue identified a need to advocate for Lariko (the patient) when she felt the doctor was not speaking to him in the way he deserved. She expressed this by confronting the surgeon directly and becoming angry with him. She explained the rationale for her reaction:

> *I don't know whether it is the type of person I am but he could have done it in another way, I guess? Like being a bit more- aw I just felt like, yeah it was just like "Next!”... you know, don't look at him, look at him like nothing (Misty-Blue).*

For Jane and Patricia, advocacy came in the form of repeatedly following up with HCPs to ensure that their loved ones were getting the best and most prompt treatment possible. Patricia established regular email contact with the nursing staff to push for an earlier surgery date for her husband, while Jane proactively asked about additional treatment for her mother based on the results she had seen of the possible extent of her cancer. Jane explained:

> *I remember after both operations in a few days we sort of went "okay, well what about chemo?"...Because what we had seen also was a letter that had arrived and it had actually shown- we had actually seen that on a couple of areas they said light staining. So, we were thinking "ah yip she needs chemo" (Jane).*

In their qualitative study of patients receiving bad news of haematological cancer, Randall and Wearn (2005) reported that family members could be an advocate to support the patient when they share the news of cancer with their family and friends. The current study extends the advocacy role of the family to include ensuring their loved ones received interpersonal and medical treatment from HCPs that aligned with family members' expectations.

Overall, the superordinate theme, 'guardian to the vulnerable patient', illustrates that family members see their patient supporter role as being to protect and advocate for the patient, recognising that ill-health and the emotionality of receiving bad news placed the patient in a vulnerable position. This suggests that family members are likely to value being able to be involved in the breaking bad news process and subsequent treatment to fulfil their role as protector and advocate for the patient. However, consideration must be given to the patient's wishes and respect their autonomy to decide whether to have their family involved (see the subordinate theme, *supporting patient autonomy*).

Prioritising the Patient

Family members' accounts highlighted their understanding that the patient was the priority when bad news was given. As such, family members spoke about directing their attention, and that of the HCPs, towards the patient during the bad news consultation ('all attention on the patient') and supporting and respecting patients' decisions ('supporting patient autonomy').

All attention on the patient. During the delivery of bad news, it was important to family members that the patient was the focus of attention, as the bad news was directly about their health and future. Fiona and Ethel recalled having almost tunnel-vision on their loved ones when the bad news of their cancer diagnosis was given. Fiona explained:

> *It was sort of like "woah" and then I could see Mark, but it was more or less like there was nothing else there and nothing else was happening. And I just was looking at his face and it just dropped and went white (Fiona).*

Family members appreciated when the HCPs delivering the bad news were also directly attending to the patient, as they believed should be the case. This was indicated to Patricia by the HCP’s eye contact, and to Jane by the surgeon’s posture and gestures:

> *'Cos he was looking at Wayne and Wayne was the person that he needed to be speaking to, so he made eye contact with you aye? (Patricia)*
>
> *But the surgeon was lovely, like she sat right down beside Mum, she held Mum's hand, she um spoke very, very lovely, just so kindly (Jane).*

Family members utilised, and recalled HCPs utilising, verbal and non-verbal attending behaviours (i.e., eye contact, spatial position, physical touch, and tone of voice) in their interaction with the patient to communicate that the patient was the focus of attention. Previous literature on the use of non-verbal communication skills highlights cultural variation in what is considered appropriate. For example, Fujimori et al. (2007) reported that Japanese patients preferred no physical touch from their HCPs when bad news was delivered. While non-verbal communication skills were identified as important by family members in the current study, the cultural context of the patient must be considered for these to be appropriately used.

Supporting patient autonomy. It was important to family members that the patient received the care they desired, which meant supporting and respecting the patient’s ability to make autonomous decisions. This was the basis for Patricia being the collector of information on her husband’s behalf:

> *My role right from the start was getting all the information I could and just helping with the decision because it wasn't- as much as I had input, it wasn't*

> *my decision. It had to be Wayne's decision to make in the end 'cos we were just collaborating together, I guess (Patricia).*

For Misty-Blue, respecting Lariko's autonomy meant accepting that he did not want her to attend his consultations with him following an incident where she got angry with the doctor. She explained:

> *Yeah, but I do agree why Lariko didn't want me to come again, because you know, it's not me going through this. So, I understood that whole-heartedly, yeah. I just felt like ah I'm just putting pressure on him. 'Cos he's like "ah no you're not coming, you stay home" (laughing). But that's alright. So, I haven't been again, yeah (Misty-Blue).*

These two examples demonstrated that family members in this participant group respected the decision-making of patients during the process of receiving bad news and making treatment decisions. This aligns with a patient autonomy model of healthcare that has been described in the literature as common in Western culture (Windsor et al., 2008).

Overall, the superordinate theme, 'prioritising the patient', illustrates that family members oriented their care towards the patient, attending to their needs and respecting their autonomy during the bad news process. Family members also appreciated when HCPs demonstrated a similar orientation during the breaking of bad news. This suggests that family members in the current study viewed the patient and their needs as the priority when they are given bad news, aligning with a patient-centred model of care.

Susceptible to Being Impacted

Family members recognised that they were also susceptible to the impact of receiving bad news, requiring support themselves in order to continue to effectively fulfil their role as supporters ('supporters require support too'). Similar to patients' accounts, family members spoke about coping in different ways that aligned with their individual style ('matching support to individual support needs').

Supporters require support too. Being the primary provider of support for someone who had received bad news about cancer was spoken about as a challenging role for family members. William described facing some difficult times as a supporter when having to constantly keep his partner’s spirits up as they went through the cancer process:

> *I don't know, I think it depends- some nights when I wouldn't get sleep, be waking up sleep-deprived, probably thinking subconsciously in my dreams and all sorts of things. But yeah, there were periods when I was lower and thinking "god I'm not- can I, you know, face another day of telling, you know (William).*

Given the need for family members to receive support, William and Ethel expressed benefitting when HCPs recognised their support needs. Ethel explained the support she received from the nurses at the bad news consultation in the following dialogue with her partner:

> *Albert: But they were supportive to you as well, weren't they?*
>
> *Ethel: They were, yeah. They were asking me how I was. And afterwards I thought, "they must have seen the shock on my face" 'cos I just didn't know what the hell to do basically.*

Family members mentioned appreciating receiving emotional support from others who were not present at the breaking bad news encounter, but became involved following this. For Patricia and Fiona, it was not until someone external to their family offered them support directly that they could express their own emotions. Fiona explained:

> *When Mark left and I got back out with [friend], I just broke down 'cos it really did- for me, it had hit the moment when we actually left when he had been diagnosed, it was real. It was really real. But then it had become even more so like, "okay, he's going for an operation" and I hadn't stopped to think because nothing was going to go wrong. Nothing. Everything was going to be 100% positive. And then probably having [friend] there, it was*

> *that crutch, when you can show a bit of emotion. You can let go a little bit and think, "hey, things might not go 100%." Yeah, but he was great because we went for a big long walk right around and we just talked the whole way and it was all just so positive. Yeah, just what I needed (Fiona).*

Fiona's account of feeling as if she had to remain emotionally strong in the presence of her husband to support him is not uncommon for family members. Matthews et al. (2019) reported that family who want to protect the patient, as was the case for Fiona, felt expressing emotions could be seen as a sign of weakness in their supporter role. This expectation potentially places increased pressure on family members who may find receiving bad news about their loved one's cancer and the implications, emotionally burdensome.

From a more practical perspective, the flexibility of Patricia's and Ethel's employers was experienced as a significant support for them to be available to care for their loved ones. Ethel recalled:

> *Well I got quite a lot of support from work. The people I work for have been amazing…. He [boss] sat there and said, "right, okay. Whatever time you want off, we will get someone in, a temp, you know, learn your job, what to do while you are waiting for the operation." ...I said to them, "I really want to save my time off until he comes out of hospital so I can look after him when he comes back." So, they said, "don't worry about that. We will negotiate your holidays" (Ethel).*

Family members' expressions of the challenges that came with being a supporter were consistent with literature that suggests there is an emotional burden to being a carer for a cancer patient (Stenberg, Ruland, & Miaskowski, 2010). Family members' need for emotional support at the time of receiving bad news was consistent with models for breaking bad news that recognise the importance of HCPs giving support to family members present (Rabow & McPhee, 1999; Villigran et al., 2010). However, the current findings also suggest that family members have a need for ongoing support as the patient progresses through treatment. While family members in the current study received this support from their friends and employers, it would be valuable for HCPs to consider how the ongoing support needs of family members could be met.

The current findings also pointed to the potential complicating factor of family members not expressing their emotional needs in an effort to be supportive of the patient, making it challenging for others to know when family members are in need of support. This suggested that family members have a role to play in making their needs explicit, while HCPs offer support to family members as part of a standard package of care following the delivery of bad news.

Matching support to individual needs. Family members spoke about coping in different ways with their loved one receiving bad news. This variation was illustrated by William, Patricia and Jane. William identified himself as an introvert, so wanted support from others to align with this. He described:

> *And I'm an introvert by nature so I don't call for other people, I'd prefer to try cope on my own as best I can and ah so I don't really get a lot of satisfaction from people coming and saying "hey are you alright?" or going- we have other friends that go the other extreme "ah you poor darling" when you are sort of building strength up and they come and start and you end up comforting them (laughs). So sometimes I would rather just be just with a few technical people and talk with them rather than friends- well-meaning friends (William).*

Patricia described herself as coping by knowing what the next steps were, feeling supported when the HCPs explained the treatment options to her, following her husband's diagnosis:

> *I'd thought about it and then I was like, "righto, what's next then?" It's pretty much like something happens in our lives and it's like, "well okay, what's the next step? How can we fix this?" (Patricia)*

By contrast, Jane coped by not thinking too far into the future, taking a short-term view of what needed to be done:

> *Because you sort of take each day as it goes- "okay what do I need to do today, what do I need to do, okay and tomorrow" you know, that sort of short sight, that short- you know (Jane).*

These family member accounts of the various ways they coped suggest that a 'one-size-fits-all' approach to providing support to family members in a breaking bad news context will not be appropriate. Similar to the findings from the patient group, family members require tailored support based on an assessment of their individual support needs.

Overall, the superordinate theme, 'susceptible to being impacted', highlights that, while family members might primarily be in the role of supporting their loved one with cancer, they too require support. The limited existing literature on family members' experiences when their loved ones' receiving bad news has meant that their needs and ways of coping have not been well defined (Matthews et al., 2019). The current findings, therefore, point to family members' need for support regardless of whether they overtly express this or not, and that support be tailored to their individual coping style.

Summary

Three superordinate themes were identified in family members' accounts of their experiences of being present during the process of their loved one receiving bad news. The first theme, 'guardian to the vulnerable patient', highlighted that family members had a strong drive to protect and advocate for their loved one during the diagnosis and treatment process. Family members valued taking this active role; however, they also needed to respect the patient's wishes and autonomy to decide if they were to be involved in this way (as outlined in the next theme).

The second theme, 'prioritising the patient', illustrated that family members' focus was on the patient during the breaking bad news process. This was done so through family members and HCPs attending directly to patients' emotional needs and family members upholding patients' autonomy in decision-making. This can be seen as family members subscribing to a patient-centred model of care.

The third theme, ‘susceptible to being impacted’ established that family members are impacted by being part of the bad news process and require support during, and following, the disclosure of bad news in a manner that is tailored to their needs and style of coping. However, the process could be complicated by family members not always making their needs apparent, which may arise from family members wanting the needs of the patient to be the focus (as seen in the previous theme). This suggested that family members need to make their support needs known and HCPs should consider offering support to family members as standard practice.

Overall, the way family members spoke about their experience of receiving bad news indicates that they have a dual understanding of who is impacted: the patient and themselves. They understand their role in the bad news process as prioritising the patient and being an important provider of support, but also requiring support themselves to enable ongoing support of their loved one.

Healthcare Professionals

Six superordinate themes were identified across surgeons’ and nurses’ accounts of delivering bad news to patients and patients’ family members about cancer. These were labelled ‘no situation the same’, ‘no standard delivery approach’, ‘organisational variables constrain care’, ‘bad news as a team-based task’, ‘psychological mindedness in a medical exchange’, and ‘the personal toll of a professional task’. Each of these superordinate themes, and corresponding subordinate themes, will be outlined below.

No Situation the Same

Consistent across HCPs’ accounts was a shared understanding of how varied each instance of breaking bad news was. The delivery of bad news differed based on the variability of each patient’s situation (‘navigating variability and unpredictability’), requiring HCPs to tailor the breaking of bad news to meet each patient’s needs (‘the art of the tailored delivery’).

Navigating variability and unpredictability. Surgeons and nurses explained that the uniqueness of a patient’s situation was informed by numerous factors. Firstly, patients varied in their specific cancer care pathways and this determined the setting and context in which they were told the bad news. The various settings for delivering bad news to patients were described by Jazz and Hamish:

> *So, everybody is different. It can be an endoscopy. The patients that we work with, it can be in a surgical clinic. It can be an acute admission on the ward in a four-bedded room (Jazz, nurse).*
>
> *Okay 'cos there are a couple of places. On the ward is one, so patients post-operatively or are in acutely who have had scans most commonly and it shows up something that is bad news. So that's one place. The other is down here in outpatients where we are seeing a lot of patients. So, I guess there is different experiences in different places (Hamish, surgeon).*

Nurse Kathy, and surgeon Jeremy, spoke about how the post-surgery context produced variability in patients' recall of the news they were told, likely due to sedation. Jeremy explained:

> *We get a large number of letters from medical oncologists in particular saying, "I've seen Mr. Brown in clinic today and he was quite unaware that his cancer had spread to his liver or that his condition was terminal." Often an astringent comment that we have failed to inform patients adequately. Well, that's not true. We do inform patients, but there is clearly a period of time following surgery where patients can be told and they appear not to register information (Jeremy, surgeon).*

Secondly, patients varied in their reactions to the news, which nurse, Jo, and surgeon, David, spoke about as being unpredictable. Jo explained:

> *You just can't, you can't plan it. The people that you think might have been the most together can sometimes be the people who fall apart. And those that are falling apart actually find comfort when they know because they can actually hang something on what they've been feeling and what they are*

> *going through. And they are like, "thank goodness I've actually got something that's made me feel as bad as I've been feeling (Jo, nurse).*

Edward and Kathy expanded on this by talking about each patient requiring different lengths of time for their appointments based on their reactions:

> *There are times when the whole thing can take a minute because they kind of knew it was coming and you've explained it before, whilst they are not ready to confront the issue yet and want to rather make another appointment to talk about it. So, you know, it can be quick or it can take forever. It can be easy; it can be hard (Edward, surgeon).*
>
> *Um, some people stay and have a cup of tea and a cry and you know, sort of try and get their heads around it. Yeah so everyone's different really (Kathy, nurse).*

This finding highlights that HCPs experience having to break bad news in a wide variety of situations, varying considerably based on a patient's care pathway and reaction to the news. As such, HCPs spoke about needing to be flexible in their approach in response to individual patients' situations and manage the unpredictability of how the process might unfold. Villagran et al. (2010), the authors of the COMFORT model, argue that achieving true adaptation and reciprocity in the breaking bad news encounter requires moving away from linear or algorithm-based models, such as the SPIKES (Baile et al., 2000), to applying overarching principles of communication. The current findings offer support to HCPs training in, and applying, communication principles for breaking bad news given how variable each patient's situation can be.

The art of the tailored delivery. The variability of each instance of bad news meant that HCPs spoke about needing to carefully consider the needs of each patient and adjust their delivery accordingly. While the bad news interaction involved a considerable amount of science regarding diagnosis and treatment planning, correctly tailoring the delivery of bad news was seen as an 'art' that was challenging to get right. Surgeons, Nathan and Jeremy, explained:

> *So how I break the news to you would be different from how I break it to somebody else. I think that's the skill, the art of being a good clinician is tailoring what you say to the person, so you are trying to meet them at their level… Because I think as part of being a good doctor and a good nurse and good health professional is being able to, as I said, be able to speak at that person's level, use analogies that they would understand or terms of reference that they would get (Nathan, surgeon).*

> *We do try and match what we anticipate, what we think the patient will be most appreciative of. In other words, how we go about it. We try to tailor it to our individual patients, but we often get that process of matching the news and how we break it to what we thought the patient would like, horribly wrong (Jeremy, surgeon).*

Tailoring their approach required HCPs to be perceptive of the patient's needs. Surgeons, Hamish and Edward, explained the variables they considered when tailoring their delivery approach, with Edward outlining the fact that this has to be judged in the moment, not planned in advance:

> *I try to judge with the individual how much they are taking in and by seeing what sort of questions they ask and their general demeanour gives a fair bit away (Hamish, surgeon).*

> *There's a lot of flying by the seat of your pants. For instance, my style of disclosing bad news to one patient might be completely opposite to the way I do it for another. And it depends on many things: my understanding of where they are at in their head, how old they are, what their level of education is, what rapport we have, what I believe their understanding is and what they are capable of understanding. So, all sorts of things. So, I don't have- I really don't try to have a one-size-fits-all solution…It's like you say, it really is a process of minute adjustments. It's a bit like, "how do you*

> *kayak down a river?" Well, you take the turns you've got to take. You can't really plan it four days in advance (Edward, surgeon).*

Both surgeons and nurses spoke about the importance of being perceptive to when a patient has become too overwhelmed to take in information and subsequently adjusting their delivery approach. Jackie explained:

> *Some people sit there and you can see it on their faces, they are not taking anything in. They are a stunned mullet, there's nothing there. Yip, they're overwhelmed. You read what's in front of you. If that patient is completely overwhelmed, you leave it at that stage and you say, "look, I'm going to make an appointment and you're going to come and see me again, okay? Alright, and we are going to talk this through again." Because they just want to go home, they just want to go (Jackie, nurse).*

Attention to the patient's cultural needs was also part of a tailored delivery. Surgeons, Edward, Hamish and Jeremy, and nurse, Jazz, spoke about being aware of different cultural considerations in bad news encounters, such as communication barriers, interpretation of eye contact, the emphasis placed on family, and expectations for full disclosure. Jazz explained the challenges of getting cultural nuances correct:

> *Yeah and that's not always easy is it because there are so many layers to culture as well. You know, some Chinese people will not tell their elderly parent that they've got cancer and that's always difficult. And I remember working with a Chinese student nurse and I had a lady with a stoma and we were talking about sexuality and the lady was in her late sixties, and the student nurse said, "in our culture, we would never talk with an elder about things like that." So, it is trying to find what is the right thing. I mean, young people, they've got a different culture too, yeah (Jazz, nurse).*

Given all the variables that need to be attended to in order to successfully tailor the delivery of bad news to a patient's needs, HCPs had to carefully consider all aspects of the encounter: who, where, when and how. Nurse, Jo, explained this in the following extract:

> *But what is always in the back of my mind is "how are we going to do this? Where are we going to do this? When are we going to do this? What's best? Who do they need to be there for it too?" (Jo, nurse).*

HCPs' awareness of the need to tailor the delivery of bad news to the needs of the patient aligned with previous literature (Bousquet et al., 2015; Matthews et al., 2019) and what patients and family members in the current study wanted from their HCPs at the time of receiving bad news. To achieve this, HCPs in the current study identified the need to assess their patients' needs during the bad news consultation and adjust their approach accordingly. This finding lends support to existing qualitative literature that has called for HCPs to be trained in assessing and responding to individual patient needs when breaking bad news, moving away from a recipe-based delivery approach (Datta et al., 2017; Mishelmovich et al., 2016; Oikonomidou et al., 2017).

Overall, the superordinate theme 'no situation the same', highlights that HCPs recognise the diversity of patients' situations when bad news is delivered and the need for a tailored delivery approach. This finding suggests that delivering bad news needs to be approached with flexibility, assessing and responding to patients' needs in the moment. HCPs should be supported to develop these skills, as this can be a more subtle and challenging 'art' for HCPs to master than ensuring that necessary content areas are covered in a bad news interaction.

No Standard Delivery Approach

HCPs spoke about the differences in how each clinician approached breaking bad news. HCPs referred to two main reasons for having an individual approach: who they were as an individual ('delivery style reflects the deliverer') and what they had learnt from experience with breaking bad news over time ('experience as the teacher').

Delivery style reflects the deliverer. The approach HCPs took to breaking bad news was understood by HCPs to be influenced by factors inherent to the person delivering the news, such as their personality and natural communication skills. Surgeons, Hamish and Nathan, explained:

> *I think it would be different for everybody depending on their personality (Nathan, surgeon).*
>
> *So, I think some people are born naturally good communicators and intuitive to what the real emotions are and others aren't (Nathan, surgeon).*

This suggested that HCPs in the current study understood the approach to breaking bad news as primarily related to who they were as people, rather than influenced by specific training they had received. Edward used this understanding as the basis for explaining why breaking bad news could not be formulaic:

> *I guess in a way I am a firm believer that it's mainly being a human being and it's hard to sort of come up with a formula for being a good human being (Edward, surgeon).*

However, the perspectives of the surgeons in the current study may have been influenced by the fact that the majority of them reported not receiving any formal training in breaking bad news (see next subordinate theme).

Training programmes on breaking bad news make the assumption that delivering bad news is a skill, and like any skill, can be learned if taught appropriately (Harden, 1996). As Buckman (1984) wrote of breaking bad news, “it is a skill (not a divine gift) and it can be taught like any other aspect of medical care” (p. 1599). The current findings suggest, however, that HCPs perceive that there may be an advantage for those who interpersonal communications skills occur naturally.

Experience as the teacher. Surgeons and nurses understood their individual approaches to breaking bad news as arising from the experience they had in their role, as most had not received any formal training. Edward explained that experience gained through repeatedly breaking bad news over his career was how he came to have his particular approach:

> *By getting old. Literally, okay. Just doing it over and over and over again. I have had absolutely no formal training in breaking bad news (Edward, surgeon).*

For Jo, her nursing role involved taking responsibility for delivering bad news at times. She explained that her training in how to do this came from observing her medical colleagues. Jo explained:

> *So, I guess, the training question is that it may be that experience thing…what you've seen work well, just copy that. Just absorb that (Jo, nurse).*

While Edward viewed his experience as an effective teacher of the skills needed to break bad news, Nathan was unsure whether experience functioned more to increase his comfort with the task rather than directly improving his skills. These perspectives are presented in the following two extracts:

> *Yeah, so I am aware that there are such guidelines, I am aware that there are such courses, and I wouldn't mind going on one, but I haven't done it and I don't think I am nonetheless very bad at doing it (Edward, surgeon).*
>
> *I am much more comfortable doing it now. But it is probably because I have just done it numerous times. Whether I have got better at doing it is the million-dollar question and I may have not got any better at it, but because I have had to do it, you just get more comfortable with breaking the news (Nathan, surgeon).*

For the HCPs in this study, their lack of formal training may have meant that they had to rely on experience to be their teacher, through observing and learning from others (an apprentice model) and repetition. Recent literature has identified an apprentice model and trial-and-error as the way many HCPs have developed their approach to breaking bad news (e.g., Datta et al., 2017; Griffiths et al., 2015; Mishelmovich et al., 2016).

However, as the surgeon, Nathan, suggested, experience with breaking bad news may not necessarily equate to an improvement in skills. Studies have reported qualified doctors and nurses can feel they have inadequate skills to effectively break bad news (e.g., Friedrichsen & Milberg, 2006; Banjeree et al., 2016) and desire further formal training (Monden et al., 2016). Therefore, while experience was important for how the HCPs in the current study developed their individual approach to breaking bad news as they did not have any formal training, this may not be a replacement for receiving communication skills training.

Overall, the superordinate theme ‘no standard delivery approach’, establishes that HCPs each have their own ways of breaking bad news; this results from who they are as people, their experience of repeatedly doing this task, and learning from observing others. It is important to account for the possibility of a cohort effect in this finding, as most surgeons had trained many years ago and reported no formal training in breaking bad news as part of their medical school curriculum. As such, this theme likely points to the role of person-specific variables and experience over time in shaping a HCP’s individual approach to breaking bad news, rather than commenting on the value of formalised breaking bad news training programmes.

Organisational Variables Constrain Care

HCPs contextualised their experience of delivering bad news as occurring within the constraints of the resources available to them. They spoke about breaking bad news being compromised by having insufficient time to do this task (‘time as a scarce resource’), the inappropriateness of the physical environment (‘limitations of an unsuitable environment’), and the high workload expectations placed on them (‘workload demands erode empathy’).

Time as a scarce resource. All of the HCPs interviewed emphasised the demands on their time and the impact this had on the quality of the care they were able to deliver at the time of breaking bad news. Jeremy explained:

> *We are under immense time pressure at both an inpatient and an outpatient venue, and the worst thing for breaking bad news is to hurry the process (Jeremy, surgeon).*

Both surgeons and nurses spoke about the inadequacy of the 15-20-minute time slot they are allocated to break bad news to a patient, which often resulted in them going overtime and delaying other patients. Hamish explained:

> *Okay, can I start with some of the limitations? One of these is time constraints. And that would be the biggest um the appointments are all booked up, there's ah no knowledge, I guess, of the person booking them what the appointment is for and so a simple follow-up for something is given the same time-space as a more complex thing when there is bad news to be given. So, I usually try and let it take the time it needs ah, but I am always conscious of the time pressures of people waiting (Hamish, surgeon).*

HCPs were acutely aware of the negative impact time constraints in the public health sector could have on their patients. Surgeon, Edward, used a comparison to the service he provides in his private practice to highlight this:

> *Well, as in my private practice, I let them go when they are ready. You know, if I say to them, "I don't think I can add much, I don't think you need to make an appointment to see me, but would you like to?" And they say, "ah yeah, I'd like to for the comfort and reassurance." I say, "okay." But in this setting, I have to say, "I am not adding value anymore. I will be kept informed and I am available if I am needed, but I am not going to schedule any more appointments." And it is clearly a case to many of them, "okay, so I am really dying, am I? It's all over now. All hope's gone" (Edward, surgeon).*

HCPs had to navigate the clash between economic imperatives placed on them by the healthcare system they worked for, and the humanity they wanted to show towards their patients during, and following, the delivery of bad news. HCPs had to find ways of resolving this tension, which for Edward involved trying to hide system limitations from his patients, and for Jeremy, involved him adopting realistic expectations of what he could achieve. They explained:

> *Sometimes I will have to say, "I understand that you have a lot of questions and so-and-so can help you with them. I have to get on, but I'd like to see you again and talk about them later and bring your family along." That kind of thing. So, you know, I try to conceal the limitations of the system as far as I can (Edward, surgeon).*

> *So somewhere along the way, there is a middle ground where you have done your best with the scarce resources you've got. And so that's what we try and do (Jeremy, surgeon).*

Insufficient time to break bad news as a result of organisational demands has been recognised in the literature as a key concern for oncologists (Bousquet et al., 2015), suggesting that this is a pervasive issue that HCPs experience. Numerous qualitative studies have reported that patients want to receive bad news in an unhurried manner (e.g., Abazari et al., 2016; Chircop & Scerri, 2017; Hanratty et al., 2012), but given time pressure, this may not always be possible.

The existing literature and the findings from the current study establish that being given sufficient time when bad news is broken is highly valued by both patients and HCPs, but that this is invariably in short supply, despite HCPs' desire to provide this. This points to the role of healthcare organisations in prioritising the allocation of time for breaking bad news conversations and follow-up appointments to help support HCPs to deliver bad news in a way that aligns with both patients' needs and HCPs' values.

Limitations of an unsuitable environment. HCPs spoke about the importance of the physical environment when breaking bad news, and the negative impact of an unsuitable environment. Jazz explained the environmental constraints of their hospital:

> *Obviously, room availability is huge. The setting in which conversations are being held is very important. We went around the hospital last year and none of the wards have an allocated area, it is always you know, "we have got a lunchroom that can be used." So that's for me, when it comes to the re-design of the hospital, that we keep bringing it up (Jazz, nurse).*

Both nurses and surgeons identified that the environment in which they delivered bad news was limited in terms of privacy, soundproofing and the capacity to accommodate large groups. Nurse, Jazz, and surgeon, Edward, explained:

> *If it is the surgical clinic setting, the walls are very thin so you can hear what's been discussed next door. So, I mean in the wards we pretend that these curtains are soundproof but they are obviously not, but we pretend to give them some privacy (Jazz, nurse).*
>
> *Yeah, and we don't, you know, it's not like we can say, "ah we've got a bunch of people, let's use the big room." You end up with people sitting on beds and standing and all that stuff. It can be, this facility is appalling, it's absolutely appalling. I complain about it every day and it limits what we do in every way. It is unsafe, it is uncomfortable, unpleasant to work in, um and- but that's a fact so (Edward, surgeon).*

Nurse, Kimberly, explained how the limited size of rooms could impact providing culturally appropriate care for Māori patients and their whānau:

> *It's not very big. There's been a few instances when um we've had to try accommodate big Māori families and just try and find something bigger. I had one instance when we had about 15 people in the room because the patient wanted those people with her, all her whānau… It can be very difficult, it's not always possible depending on what is going on in the department (Kimberly, nurse).*

HCPs recognised that, on the one hand, the environment they worked in directly impacted the quality of the care they were able to provide when breaking bad news; on the other hand, it was a fixed constraint that they were unable to change. The need to update the hospital facilities highlighted by the HCPs in the current study was reiterated in a recent news report of senior doctors from MDHB urging an update to the hospital facilities (Brown, 2019). The article reported that these environmental constraints were putting pressure on medical staff, which reflected the experience of HCPs in the current study when it came to delivering bad news.

Similar to the provision of time, the current findings are consistent with previous research that has identified a private environment as important to patients (Abazari et al., 2016; Fujimori et al., 2005; Randall & Wearn, 2005) and HCPs (Bousquet et al., 2015). In addition to the importance of privacy, HCPs in the current study also emphasised the importance of having adequately sized rooms for breaking bad news with family groups. This might be reflective of the study being set in New Zealand where cultures present here, such as Māori, are known to value the involvement of large whānau groups when important information is shared. Overall, the current findings offer further support to the importance of an appropriate environment for effectively delivering bad news and suggest a need for hospitals to prioritise improving the environment for bad news conversations.

Workload demands erode empathy. HCPs experienced their high workloads as impacting the way they delivered bad news. Edward explained this challenge:

> *Now if you are in a situation where you've been up all night, you are frustrated, people are telling you that there are a bunch of unruly patients starting to complain in the waiting room etcetera, etcetera. And now you've got to go in there and calmly and compassionately convey that news, it can be hard just because your own resources are in short supply (Edward, surgeon).*

Expanding on this, Nathan explained that their personal limits were often reached by the high frequency with which they had to deliver bad news:

> *That's the one time for them, but it's the 100th time for you and it does get exhausting. I mean, communication is so important but you do get tired of communicating (Nathan, surgeon).*

Nurse, Jackie, and surgeon, Nathan, articulated that there were consequences for HCPs having demanding workloads in the form of compromising their ability to be empathic towards patients:

> *The harder you work a clinician; my impression is that the empathy level goes down. So, you push the clinician to the edge of breaking point, it gets very task-oriented… So, if an organisation says, "great, you're giving 100%, but we want 110," they are not going to get the best out of that clinician… You cannot push the clinicians, like they have been doing, with unrealistic expectations and expect them to be able to sit there and do the best of their ability (Jackie, nurse).*
>
> *I think it is easy in our job to become emotionally, empathetically challenged. You've just got so much- what's the term I am looking for? You are just exhausted, you are always pouring out, "here is one more person who needs you to pour into their lives," but there is no in-filling into your own life. I think that's hard (Nathan, surgeon).*

Consistent with the current findings, qualitative studies have reported that high workloads can result in HCPs becoming fatigued, task-focused, and less empathetic in bad news interactions (Banerjee et al., 2016; Ehsani et al., 2016; Oikonomidou et al., 2017). In a review of the literature, it was found that patients wanted to feel genuine empathy from their HCPs when receiving bad news (Matthews et al., 2019), but this may not be possible if HCPs are under excessive work demands. This finding highlights the need for healthcare organisations to better manage HCPs' workloads and emotional wellbeing if HCPs are to deliver bad news in a way that meets patients' needs.

Overall, the superordinate theme 'organisational variables constrain care' highlights the time constraints, environmental limitations, and workload demands under which HCPs are expected to deliver bad news that are experienced as directly impacting the quality of their delivery. HCPs spoke about these demands as clashing with their personal values and compromising their level of empathy. This theme illustrates that the onus is not solely on individual HCPs to improve the delivery of bad news. There is a vital role for healthcare organisations in providing a suitable environment and workload expectations that allow for sufficient time for breaking bad news consultations and follow-up appointments, and mitigate HCP fatigue and possible burn-out.

Bad News as a Team-Based Task

HCPs spoke about the importance of working as a team in order to provide the best care possible for the patient when breaking bad news. The team approach involved surgeons and nurses having a shared understanding of the different roles they fulfilled (‘doctor as deliverer, nurse as supporter’), and the use of the patient’s family as a resource for communicating important information to the patient (‘family as a resource’).

Doctor as deliverer, nurse as supporter. There were clearly defined roles that surgeons and nurses held when working together to deliver bad news. The surgeon was seen as the one to deliver the bad news, while the nurse was viewed as providing emotional support. There was a common understanding among all of the interviewed nurses and surgeons of these roles. Nathan explained:

> *I think it is one of the jobs that a doctor should do. I think if someone’s going to have- I think as part of the team, someone has to be seen to be the one who is the bearer of the bad news, whereas the Clinical Nurse Specialist, in our structure, I'd see coming alongside and supporting the women. So, if they haven't had to break the news, it just, personally my opinion is that it makes them a more approachable person. They are not always being reminded that that's the person who broke the bad news (Nathan, surgeon).*

Nathan outlined the rationale for having clear roles for the surgeon and nurse as emerging out of careful consideration for the patient being able to separate the deliverer of bad news from the person providing ongoing emotional support. An additional consideration for having these clear roles was the time limitations surgeons had. This was described by Clinical Nurse Specialist (CNS), Mariah:

> *Most people can see that we do work as a team, the surgeon- and that's the other problem with being told in a clinic like that is that they've got 30 other*

> *people to see as well and so they really truly just don't have the time to sit and go through everything, so that's why I'm kind of the person that helps to maybe give some insight into what happens next (Mariah, nurse).*

The role of the CNS was well understood by surgeons and nurses, and their ability to give patients more time distinguished them from the role other nurses fulfilled. Kimberly explained:

> *So, we actually find it quite difficult because we've been left with the patient but we actually don't have time to spend with them because the rest of the clinic is still going on and we actually need to get- because we might have another 20 patients to see in that morning. So usually we only get to spend less than 5 minutes in reality with that patient after they've had that diagnosis and then we send them off. So that's when the Clinical Nurse Specialist is so important because they usually have a bit more time with them and then that person is then their contact person (Kimberly, nurse).*

While there were clear roles that the surgeons, CNSs and nurses fulfilled, there was a new initiative being trialled for one CNS (within one department), Jo, to deliver bad news, as she often had developed a relationship with the patient and had more time to spend breaking the news. She explained:

> *The fact that I could have a room for an hour and not be interrupted was also a plus. The fact that I had built that relationship with them during their journey and through their diagnostics made sense that I was the person that was there (Jo, nurse).*

This represented a significant shift in the typical role taken by a nurse and, thus, Jo spoke about having to prove her competence at this task and earn the trust of the surgeons she worked with:

> *So, it's building the trust in them I guess that I am doing okay, or doing it as well as them if not better than them, in a timely fashion (Jo, nurse).*

The effort she had to go to in order to move from a nurse's role into one typically held by the surgeon, could be seen as demonstrating how embedded these roles are.

Studies from Iran (Abazari et al., 2016), the UK (Mishelmovich et al., 2016), and Australia (Clayton, Butow, Arnold et al., 2005a) report doctors as the ones who deliver bad news, with other HCPs, such as nurses, taking a supporting role. This suggests that these roles were an expectation not only held by HCPs in the current study, but by patients and HCPs internationally. Having a shared understanding of the roles of each member of a healthcare team (and respecting these) is identified as one of the core principles underlying an interdisciplinary team approach (Nancarrow et al., 2013). It is possible that surgeons and nurses in the current study having a clear understanding of the roles each person fulfilled when bad news was delivered, helped them to function more effectively as a team.

Family as a resource. HCPs spoke about the importance of having family/whānau members present when they delivered bad news to a patient, conceptualising them as a resource for the transmission of information. Both surgeons and nurses commented on how useful family were to take in information when the patient was too overwhelmed to, after being told bad news. Nathan and Jeremy explained:

> *In the consultation itself, I would see them being the people who are taking in the information you are passing on to the person involved because the person involved is almost always not really there once you've told them they've got cancer. So, it is having somebody who can relay that information on to the person later on… So, you are really- although you are speaking to the patient, it is really the family you are directing the conversation to initially because you are counting on them when they go away. And that's why you write things down, you usually give it to one of the family members (Nathan, surgeon).*

> *The family is the best protective mechanism against the patient receiving information and distorting it or in some way not processing it in a way that*

> *they have a true reflection of what their disease is doing. But the families are involved and invariably they talk with their loved ones about their cancer (Jeremy, surgeon).*

Nurses in the current study outlined that involving family required careful consideration. Kathy and Kimberly talked about inviting family to be present at the appointment as potentially causing a dilemma: they did not want to distress the patient by alerting them to the 'bad news', but they also did not want the patient to be alone. Kathy explained:

> *It is very difficult for us to ring the patient up and ask them to bring a support person with them because then they know they are going to get bad news. So, it's very difficult to do that um but then it's difficult for them to get the news on their own as well (Kathy, nurse).*

Jo articulated how varied families could be, and the need to be able to manage family dynamics and different ways of coping, potentially complicating the breaking bad news process.

> *But the ones with family, it's varied. It is as varied as each individual patient as each family member and how they are going to cope with things and the dynamics amongst families too (Jo, nurse).*

Reflective of the complexity of involving family identified by HCPs in the current study, Bousquet et al. (2015) outlined that oncologists saw family as being both a facilitator of faster information delivery and a potential barrier to full disclosure to the patient and acceptance of palliative care. While family did not present the same barriers in the current study, the current finding suggests that HCPs recognise that using family as a resource during bad news consultations can be helpful, but is not always straight-forward.

Overall, the superordinate theme 'bad news as a team-based task' illustrates the different roles fulfilled by surgeons, nurses and family members when breaking bad news; all of whom could be seen as part of the bad news delivery 'team'. Surgeons were primarily understood as the ones who delivered the bad news and nurses (particularly CNSs) as providing emotional support to the patient. However, these HCP roles could shift based on the needs of the patient and time constraints, and with the support of the HCP team. HCPs could draw on family members when getting important information across to the patient, but this also required HCPs to consider family dynamics and needs. This finding suggests that the complexity of the breaking bad news process requires a team (rather than being approached single-handedly), and the roles taken in the team are driven by considering what is best for the patient within the resources available among HCPs and the patient's family. HCPs having the skills to make this assessment is, thus, important.

Psychological Mindedness in a Medical Exchange

HCPs had an awareness of the psychological aspects that were relevant to patients when receiving bad news and the importance of attending to these in the patient's care. HCPs spoke about using particular strategies to lessen the emotional impact on patients in the moment of being told bad news ('reducing the emotional burden'), as well as supporting their ongoing emotional wellbeing ('valuing providing ongoing emotional care').

Reducing the emotional burden. HCPs understood that receiving bad news was a distressing experience for patients. As such, they talked about a range of ways in which they tried to lessen the emotional burden, both in the lead up to, and during, the bad news consultation.

HCPs viewed providing empathy and validation as key components of supporting the patient, psychologically. This was illustrated in the following two extracts by surgeon, Nathan, and nurse, Jazz:

> *It is about being able to be empathetic and to convey a sense of you know, 'we are really sorry this has happened to you, you are a special individual. This is what we want to do to try and make things, you know, help you to try transition through this stage of your life (Nathan, surgeon).*
>
> *To me that looks like all the people involved have come away afterwards with a feeling that everybody has felt validated…often the bad news doesn't change, but if it has been shared with the patient and their family in a way*

> *that they go away with, you know, understanding and feeling that they have been treated well in that situation, I think is really important (Jazz, nurse).*

Another strategy to reduce patient distress was having the opportunity to form a relationship with the patient prior to delivering bad news. For Jo, this showed the value of her role:

> *I think it just speaks volumes to actually recognising that in that phase from your abnormal X-ray to being told your news, your diagnosis, that you do need someone to help navigate and help support and to build that relationship. And it just culminates that when you do tell that news, it's actually not the worst thing that would ever happen. It is part of what happens, but, you know, I don't want it to ever be a catastrophe (Jo, nurse).*

There was some variation in the specific strategies HCPs used across the participant group. Nurse, Mariah, shared the importance of mentally preparing the patient for the possibility of bad news during the investigation phase (i.e., forewarning), while surgeon, Nathan, kept the possible diagnosis to himself. In both cases, they had a common goal of helping reduce the emotional burden on the patient. Mariah and Nathan explained:

> *I will start sewing little seeds um and you know if I think I really- if we're highly suspicious when we first meet people that um things are worse than what we know, and so when we're preparing for a CT scan, which will give us that information, I'll actually say, "look, this is either gonna go one way or the other" (Mariah, nurse).*

> *At the end of the day, this probably sounds paternalistic, and I don't mean it to, I feel it is my responsibility to carry the worry until we know one way or the other what's going on. So, I do try, this is my perception, to protect the woman from needless worry that is just emotion sapping, mentally exhausting when in fact it is going to be benign (Nathan, surgeon).*

HCPs recognising the emotional impact on patients at the time of receiving bad news is not new to the literature (Bousquet et al., 2015), with many guidelines for breaking bad news including attending to patients' emotions as a key consideration (e.g., Baile et al., 2000; Rabow & McPhee, 1999; Tang et al., 2014). The current findings offer a number of strategies that HCPs used to try to reduce the emotional burden on patients, with empathy, validation, developing a patient-HCP relationship, and forewarning being consistent with the qualitative literature on what patients desired when receiving bad news (Matthews et al., 2019).

Given that there was some variation in the specific strategies HCPs used to achieve the same outcome (i.e., a forewarning of the possible diagnosis or not), it may be that an assessment of what would be most beneficial to the individual patients is indicated to decide which approach to take. This suggests the importance of HCPs having the skills to assess and respond to patients' emotional needs during the bad news encounter.

Valuing providing ongoing emotional care. HCPs recognised that receiving bad news had a continuous psychological impact on patients and ongoing emotional support was important as they adjusted to the news and implications of it. This perspective was highlighted when surgeon, Nathan, and nurse, Kathy, spoke about patients adjusting to bad news as going through the stages of grief and needing ongoing support during this. Nathan explained:

> *But I guess breaking bad news about cancer is a process rather than an event and it takes time for women, you know, stages of grief, you've got to work through all of those with the person (Nathan, surgeon).*

The provision of hope was another way HCPs saw themselves supporting patients to mentally cope on an ongoing basis. Nathan explained the importance of hope and that it needed to be realistic:

> *Because I think the greatest gift you can give anybody is hope, you just don't want to make it fools' hope, you want to make it realistic I think, so people don't waste what time they have left (Nathan, surgeon, extract 2).*

HCPs were also aware of the importance of non-abandonment for how patients coped when their cancer could no longer have a surgical intervention. Jeremy explained how this was a particular concern for him:

> *You know, at the very worst time in your life, when you know you are going to die, everyone just suddenly disappears into their holes and you are left stranded and it's a very horrible feeling. And I know I am a bit soft when it comes to that because I know most of my colleagues, as soon as someone is metastatic, "see you later, gone. Have a good life. You are not my problem anymore." Anyway, that's a personal thing actually. 'Cos you try and sort of imagine, what if it was you? Would you want to be booted out unceremoniously? (Jeremy, surgeon)*

However, the reality of the public health system's scarce resources meant that it was not always possible for surgeons to continue seeing patients for whom they were no longer providing surgical treatment to mitigate a sense of abandonment, even if this was the care they would ideally like to provide. Edward explained this tension:

> *And I feel sometimes the sense of abandonment when I say, "well look, I am not going to- I will be receiving correspondence, I will be kept in the loop by your oncologist etc." But I think that is a stressful moment for them when you step back and say, "well I am out now." And we have to do it. We cannot out of some kind of loyalty, or perceived loyalty, say, "well I'll see you again in three months" when I haven't got anything to offer. Because if I see them again in three months, I don't see someone else in three months and we cannot do that. We turn away too many referrals as it is (Edward, surgeon).*

HCPs recognition of the ongoing emotional impact of receiving bad news is congruent with literature that reported patients view breaking bad news as a process that occurs over time (Tobin & Begley, 2008) and that HCPs have a role in supporting patients to cope and adjust to the news (Matthews et al., 2019). This finding highlighted that there, however, can be constraints on HCPs providing individual ongoing emotional support to patients, particularly when patients transition between treatments or to end-of-life care. This suggests that there is a role for having systems in place to support patients so they do not feel a sense of abandonment or loss of hope as they adjust to the reality of their cancer.

Overall, the superordinate theme 'psychological mindedness in a medical exchange' highlights that HCPs have a psychological lens, as well as their medical lens, through which they viewed breaking bad news. They understood their role in lessening the emotional impact of bad news when it was delivered and supporting patients' psychological wellbeing on an ongoing basis, even if the system constrained this. The consensus between the past literature and the perspective of the HCPs in the current study on the importance of attending to the emotions of the receivers of bad news, suggests that HCPs should be equipped with the skills to assess and attend to patients' emotions and have the provision of resources to offer support to patients on an ongoing basis.

The Personal Toll of a Professional Task

Breaking bad news was a task that HCPs recognised as having a personal impact on them. When reflecting on their experience of delivering bad news, HCPs described the reasons why this task took a toll on them ('HCPs as human too') and the strategies they had developed to cope ('coping to enable longevity').

HCPs as human too. All HCPs described breaking bad news as affecting them personally, as they were, after all, only human and wanted the best for their patients. Edward and Nathan explained this in the following two extracts:

> *So, I'd say I mostly try to be a- I don't know what the term is- emotionally intelligent normal human being, not a doctor. And what would be hard for any human being is hard for me. And I don't really believe that any amount of specific training will ever make it easy to tell a young person with children that they are going to die (Edward, surgeon).*

> *The main barrier I think is that human nature is to always want the best for someone. So, when you are telling someone they have cancer, that's not the*

> *best for that person, it would be much better to say, "oh look, congratulations, you're pregnant," or "congratulations, it is a benign cyst and we can take it out and it is not cancerous." So, it really goes against the grain when you've got to tell someone something that isn't good for them 'cos nobody wants to hear that news. So, for me, that hardest bit in doing it, it goes against the grain to break bad news, I think (Nathan, surgeon).*

Surgeons and nurses both talked about their emotional reactions to delivering bad news. This was described as feelings of *"sadness"* (Hamish, surgeon) and an *"emotional tug"* (Nathan, surgeon). HCPs' reactions to delivering bad news were influenced by a number of factors. For nurses, Kimberly and Mariah, and surgeons, David and Hamish, breaking news of incurable cancer had the greatest impact. Kimberly explained:

> *Um that's actually quite difficult especially if you know- I actually find that I can cope with it quite well myself if I know it's a curable. You know, even though it is bad news, it's curable and that's quite good because you can reassure the patient that, "look, the aim of this treatment is to actually cure you so you no longer have cancer." Yeah so, but it's in those instances where it could be a terminal diagnosis and that's when it's a little bit more difficult (Kimberly, nurse).*

For Nathan and David, it was breaking bad news of a cancer diagnosis to patients of the same generation as themselves that was the most challenging, as this made them think about their own mortality. Nathan described how this felt for him:

> *So, there are some days where it feels like you're walking through life and there are bullets being fired at you from the grim reaper. They are passing all sides of you and you look around and you see women in their 50's who are being hit by these bullets and are going down with cancer or whatever and men of course as well, but yet with life you keep walking towards the*

> *final destination. So, for me the hardest bit is that it really reinforces your mortality (Nathan, surgeon).*

For nurses, Jo and Jazz, the presence of either patients' and their family members' high emotion or absence of a reaction, impacted them the most. Jo and Jazz explained:

> *I have had the Māori lady wailing at the news, which was the most spine-tingling, you know, bought me to tears just seeing her distress (Jo, nurse).*
>
> *It's when people are really very, very shocked by it and they have no idea that this was coming. But I also find it quite challenging if they are quite, "oh well", you know. If they almost, if their emotions are almost not- I find it easier if they are crying, you know. If they have a reaction (Jazz, nurse).*

A commonality across the HCPs interviewed in this study was that breaking bad news impacted them personally, with the patient's stage of disease and emotional reactions, and HCPs' own stage of life, influencing how affected they were. The literature indicates that some HCPs fear not being able to manage their own emotional reactions when breaking bad news and that this could compromise their clinical judgement (Buckman, 1992; Chittem & Butow, 2015). However, HCPs in the current study did not appear to judge their emotionality negatively; rather, it was a natural and expected part of being human in their healthcare role. This finding suggests the importance of providing HCPs with support to emotionally cope with this challenging part of their job.

Coping to enable longevity. HCPs recognised that breaking bad news was always going to be a part of their job and, in light of the personal impact of this, had to develop strategies to cope. Nurses, Mariah, Jo, and Kathy, spoke about the importance of debriefing with colleagues in order to cope, especially as professional supervision was not typically provided for nurses. Mariah explained:

> *I have- when I did my final paper of my Masters, my prescribing practicum, I had a supervisor, a clinical supervisor- or professional supervisor and that was great because I was able to- but I don't have that in a formalised way,*

> *which we should when we are dealing in this kind of environment. But um I've got great colleagues, I'm really lucky, I'm so lucky that I work within a team where we all feel the same thing so we can all debrief and sound each other off (Mariah, nurse).*

HCPs mentioned coping through deliberately shifting their focus during and after bad news consultations. Nurse, Jo, explained how she used the strategy of turning her attention from the emotionality of the news to what could be done:

> *I am a very emotional person. I think that I've learnt off my medical colleagues how to be able to give the news, I still feel it, but it's important that I put the energy into actually the solutions and the options. And so, I am able to go into that 'what's next' mode. I don't dwell in the giving of news so much (Jo, nurse).*

While delivering bad news was challenging in the moment, surgeon, Edward, and nurse, Jazz, explained that they coped afterwards by shifting their attention to other tasks:

> *Yes, it's difficult. I don't wail about it and probably 3 minutes later I have forgotten it's happened, you know, we do a lot of stuff. But yes, in the moment, it is terribly difficult (Edward).*

> *I think you, kind of, you do need to take a moment afterwards to just um take a breath or two and get on with it (Jazz, nurse).*

HCPs also outlined the value of knowing what they personally needed to cope. For nurse, Mariah, this was knowing when she needed a break:

> *I do know when I need a holiday because I'll start waking up in the night and worrying about, you know, so you know your warning signs as well so, yeah (Mariah, nurse).*

For the surgeon, Hamish, this involved knowing how much emotional energy to invest in a bad news consultation so he did not compromise the longevity of his career:

> *I think probably the flip side of having a developing a bit of a relationship with the person, you actually do feel a fair bit of empathy for them. But I guess again that is something that evolved- I don't feel like I have too much trouble turning it off when I leave…And I hope that doesn't sound cold but I think you have to develop ways to cope because you want to be in this for the long haul- well I do. And so, you know, 30-years of doing it, you wouldn't want to burn out in the first two by ah investing too much emotional energy in people and not being able to cope. So, I feel I've got the balance right for me, you know (Hamish, surgeon).*

When HCPs were asked about support services offered by the organisation they worked for, participants either knew about these and had not accessed them, or were unaware they existed. Surgeon, David, and nurse, Kathy, explained:

> *Um, I expect yes because we've got um regular advertising in our email boxes, "are you feeling under pressure?" etc. etc. etc. But I never sought it. I know, I know it's there (David, surgeon).*
>
> *Hmm not that I know of, no. I guess, just debriefing among ourselves (Kathy, nurse).*

Across the participant group, HCPs used different strategies to cope with the challenge of delivering bad news, including debriefing, shifting their focus, taking breaks, and maintaining a degree of emotional distance. In a qualitative study, Shaw, Brown, and Dunn (2013) identified that doctors can utilise problem-focused (i.e., changing or controlling the situation; PFC), and emotion-focused (i.e., minimising their negative emotional response; EFC) coping strategies during breaking bad news encounters. The current findings demonstrated the use of PFC when HCPs deliberately focussed on ‘next steps’ during the consultation and EFC when HCPs distanced themselves to not drain their emotional energy. The current study added that strategies used following, or outside of, the bad news consultation were equally important to help HCPs cope, such as debriefing with colleagues, turning their attention to the next task, and taking breaks.

The findings also highlighted that for the current study participants, generic support services offered by the organisation were either not known to HCPs or not taken up. While it is no doubt important to have these services available so they can be accessed, the range of strategies used suggested that HCPs had different needs that aligned with different coping strategies. It may be beneficial for HCPs to be taught, and utilise, the skill of self-reflection to help them identify and implement the strategies that meet their individual needs to support their emotional wellbeing and longevity in the profession.

Overall, the superordinate theme ‘the personal toll of a professional task’, highlights that HCPs experience encounters in which they have to break bad news as taking a personal toll on them. This led them to locate themselves as human in their HCP roles and necessitated them finding various ways of coping in order to support their emotional wellbeing and longevity in their roles. This suggests that HCPs need support with coping with the challenges inherent in breaking bad news, and like patients and family members in the current study, HCPs require support in a way that aligns with their individual needs and style of coping.

Summary

Six superordinate themes were identified across surgeons and nurses accounts of their experience of breaking bad news. The first theme, ‘no situation the same’, established that HCPs have to navigate a variety of different patient circumstances and reactions when they break bad news, and, due to this variation, HCPs have to tailor their approach to each individual. This suggested that HCPs needed to be flexible and assess and respond to the needs of the patient during the consultation, and be supported to develop these skills.

The second theme, ‘no standard delivery approach’ highlighted that HCPs had a variety of approaches to breaking bad news, influenced by who they were as people and their experiences with, and observations of, breaking bad news over their career. This suggested that there is not one approach to how bad news is broken and person-based variables and experience play a role in shaping a HCP’s individual delivery style. The HCPs’ lack of formal training in breaking bad news also provided an important contextualising variable for the study.

The third theme, ‘organisational variables constrain care’ outlined that HCPs have to break bad news with limited time, unsuitable environments, and high workload demands, compromising the quality of their delivery and clashing with how they would ideally like to deliver bad news. This finding pointed to the role of healthcare organisations in supporting HCPs to deliver bad news in the best way possible by providing appropriate physical environments and realistic workload expectations.

The fourth theme, ‘bad news as a team-based task’ established that HCPs approached breaking bad news to a patient as a ‘team’, consisting of surgeons, nurses and the patient’s family members, who took on different roles. Typically, this involved surgeons as the bearers of bad news, nurses as the supporters, and family members as a resource for transmitting information to the patient. These roles could shift based on what was best for the patient, the resources available (e.g., a HCP’s time), and family dynamics and needs. This suggested that a single HCP does not have to manage the complexity of the breaking bad news process on their own and the roles that surgeons, nurses and family members took were influenced by an assessment of the available resources and needs.

The fifth theme, ‘psychological mindedness in a medical exchange’ identified that HCPs could take a psychological lens to the breaking bad news process. They used a range of interpersonal strategies to attend to patients’ emotional needs during the bad news consultation and identified patients’ emotional support needs on an ongoing basis, even if limited resources constrained them providing this care. This suggested the value of HCPs having the skills to assess and respond to patients’ emotional needs, and providing access to resources to allow patients to be supported in an ongoing manner.

The sixth theme ‘the personal toll of a professional task’ highlighted the personal impact breaking bad news has on HCPs and the need to employ coping strategies that allowed them to continue performing this difficult part of their professional roles. The coping strategy used could vary between HCPs, suggesting that HCPs reflect on their individual support needs and be given access to support in a way that matches their style of coping.

Taken as a whole, it is evident that HCPs experience the process of breaking bad news to patients about cancer as a challenging task, both professionally and personally. They acknowledge that the task on its own is complex due to the need to tailor their delivery and attend to medical and psychological variables. This is further complicated by limited resources and workload demands that are beyond their control and the personal impact breaking bad news can have.

***Part One* Summary**

This group-based analysis provided useful insights into how the breaking bad news process is experienced from the perspective of being a patient, a patient's family member, and a HCP. Each group experienced the breaking bad news process through a different lens. Patients made sense of receiving bad news as being linked to the beliefs and experiences they brought to the encounter, their relational and support needs during (and in the short-term after) receiving bad news, their concern for others involved, and the long-term psychosocial implications. Family members understood receiving bad news as a process that required careful consideration of the patient and their needs, but also of the impact it had on themselves as fellow receivers of bad news and providers of support. HCPs viewed delivering bad news as a challenge professionally, in regard to the individual patient considerations (medical and psychological) required and working within organisational constraints, and personally, in respect of the emotional toll this task could take.

However, common aspects in each of these groups' perspectives were the challenges this experience presented for the group themselves and their awareness of how this affected others, the roles they saw themselves and others taking, their needs at the time, and their means of coping. The specific themes from this analysis will be re-visited in the next chapter when conclusions are drawn across the whole data set.

The next part of this chapter outlines the outcome of the second form of analysis in this thesis: interpreting a series of 'linked cases'. This approach is to directly compare the perspectives of each party involved in a single patient's case of breaking bad news in regard to aspects considered important to all during the process. It is written as the second manuscript in this thesis.

CHAPTER FIVE: FINDINGS AND DISCUSSION

Part Two:

Single Cases from Multiple Perspectives: A Qualitative Study Comparing the Experiences of Patients, Patients’ Caregivers, Surgeons, and Nurses when Bad News is Delivered about Cancer

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Abstract

Background: Qualitative literature on the experiences of those delivering and receiving bad news about cancer have revealed what these parties consider important during the process across many different patient cases. The current study aims to add to this understanding by employing a ‘linked case’ study design to directly compare the perspectives of patients, their caregivers, and healthcare professionals (HCPs) involved in a series of single-patient cases of breaking bad news.

Method: Semi-structured interviews were conducted with 13 participants (five patients, four caregivers, two surgeons, and two nurses) who formed five linked cases. Interviews were analysed using interpretative phenomenological analysis and directly compared within each linked case.

Results: Analyses identified two main superordinate themes. The first labelled ‘accurately perceiving and responding to needs’, included HCPs recognising and responding to patients’ and caregivers’ individual emotional and informational needs. The second labelled ‘carers fulfilling necessary roles’, identified the various roles HCPs and patients’ caregivers took to satisfactorily meet patients’ needs.

Conclusions: The findings suggest the importance of HCPs accurately perceiving and responding to patients’ and caregivers’ various needs and caregivers’ ability and willingness to fulfilling support roles in a way that aligns with their own resources and patients’ needs. This highlights the value of HCPs developing and applying interpersonal skills within bad news encounters, working as a team, and exploring caregivers’ resources for patient support.

Keywords: Breaking bad news, cancer, caregivers, healthcare professionals, interpretative phenomenological analysis, oncology, patients, qualitative methods.

Introduction

Breaking bad news to patients is an inevitable part of working in the medical profession, and one that healthcare professionals (HCPs) working in cancer care may face on a regular basis. There are many moments along a patient's cancer journey that could be considered 'bad news', such as receiving news of a diagnosis, test result, prognosis, relapse, or transition to palliative care (Bousquet et al., 2015). What constitutes 'bad news' for someone, and the impact of the news, can vary based on an individual's expectations for their future and longevity, current life situation, past experiences, personality, cultural and social background, beliefs, availability of support, and emotional resilience (Buckman, 1992; Fallowfield & Jenkins, 2004). Additionally, bad news can be delivered via a variety of modalities, such as in-person or over the telephone, which can affect patients differently (Salander, 2002). To capture this variation and subjectivity, a broad definition of 'bad news' is needed. Ptacek and Eberhardt (1996) defined bad news as any information that "…results in a cognitive, behavioural, or emotional deficit in the person receiving the news that persists for some time after the news is received" (p. 496).

The process of breaking bad news can be challenging for those receiving and delivering the news. For patients, receiving bad news about cancer is typically a significant emotional event, where their futures are suddenly changed, and in some cases, shortened. This can result in a range of emotional reactions, including shock, anger, sadness, denial, relief, and acceptance (Fallowfield & Jenkins, 2004; Warnock et al., 2017). Literature on patients' caregivers suggest similar emotional impacts (Buckman, 1992). However, caregivers can carry the additional burden of feeling they must withhold information from the patient or hide their own emotions in an effort to protect the patient from further distress (Friedrichsen et al., 2001; Matthews et al., 2019).

For HCPs delivering the news, the complexity of communicating bad news lies in the numerous factors requiring consideration: responding to patients' and their caregivers' emotional reactions, which they can feel fearful of and inadequately trained to manage (Alexander & Klein, 2000); adapting the delivery to meet individual patient's preferences and cultural needs (Naseem, 2018; Windsor et al., 2008); managing their emotional reactions to the bad news (Bousquet et al., 2015); and working within the time and resource demands of their workplaces (Warnock et al., 2017). Additionally, a poor delivery has been reported to impact a patient's level of satisfaction (Brown et al., 2011), anxiety (Zheng, 2011), and psychological adjustment to the news (Roberts et al., 1994).

Given the complexity of the breaking bad news encounter and the importance of this task being done effectively, numerous qualitative studies and reviews have been conducted to explore the experiences of different parties involved: patients, patients' family members or caregivers, and HCPs (Abazari et al., 2016; Bousquet et al., 2015; Furber et al., 2013; Matthews et al., 2019). Key considerations commonly reported in oncology include the setting (private, quiet, unrushed), tailoring delivery to a patient's preferences and cultural background, attending to the emotional reactions of those receiving bad news, and maintaining hope.

While this existing research points to pertinent aspects of a broad range of bad news encounters, to the authors' knowledge, Furber et al.'s (2013) study is the only qualitative investigation to date that has used a design that enabled a direct comparison of the perspectives of patients, relatives, and HCPs involved in a single patient's case of breaking bad news about cancer. 'Linking' the perspectives of these different parties within the same case highlighted whether the needs of the patient were congruent with the understanding and actions of the HCP, which has important implications for delivering satisfactory healthcare (Furber et al., 2013). While this 'multi-perspectival' approach has been applied in other areas of health (Smith & Shaw, 2017), this form of analysis, and the potential insights within-case comparisons can offer, are underdeveloped within breaking bad news in oncology.

The current study is exploratory and aims to further develop this within-case comparison analysis by implementing a 'linked case' study design to closely examine, and directly comparing, the perspectives of patients, their caregivers, surgeons, and nurses involved in the same patient's case of breaking bad news about cancer.

Methods

Interpretative phenomenological analysis (IPA) provided the theoretical framework to examine semi-structured interviews exploring participants' lived experiences of the breaking bad news process, and then to directly compare patients', caregivers' and HCPs' accounts that were linked to the same patient's case. The study was phenomenological in the sense that it prioritised the way participants made sense of their personal experience of the breaking bad news encounter; and grounded in hermeneutics, whereby both the participants and the researcher engaged in a process of interpretation to arrive at the findings (Smith et al., 2009). In support of the current design, Larkin, Shaw, and Flowers (2019) have suggested that IPA can be applied within multi-perspectival study designs to capture more complex participant experiences, while upholding the epistemological foundations of IPA. This study adheres to the reporting framework for qualitative research (see Appendix N; Tong, Sainsbury, & Craig, 2007).

Data collection

Patients and caregivers were recruited through the hospital- and community-based healthcare workers who cared for patients diagnosed with cancer at a hospital in the North Island of New Zealand. Patients were eligible to participate if they were 18-years and older and had been through a surgical treatment process for cancer that involved receiving bad news. The current study allowed patients to self-identify what they considered to be 'bad news' in their interactions with HCPs in the surgical departments, reflecting the subjective nature of this concept as outlined in the literature (Fallowfield & Jenkins, 2004). The focus on surgical departments was driven by the interests of a district cancer care group (consisting of HCPs) in getting a better understanding of the bad news processes that are followed. Patients were to be at least 3-months post-surgery so they were more likely to be in a position to reflect on their experiences without the burden of having recently received bad news and undergone surgery. Caregivers were relatives, or non-relatives, who were present when the patients received bad news within the hospital's surgical department and were 18-years and older.

Patients and caregivers contacted the primary author expressing their interest in participating, and an interview was arranged. Patient and caregiver interviews occurred four to eleven months post-surgery and were conducted in their homes, with two of the patient-caregiver dyads choosing to be interviewed together. Upon patients' consent to be part of a linked case, the surgeons and nurses involved in delivering bad news to the interviewed patients were directly contacted, inviting them to participate. For the HCPs who responded and agreed to participate, interviews were conducted individually within their place of work.

The current study sample was determined by the number of linked cases that were able to be formed from the data collected for a larger doctoral study exploring the perspectives of four different groups involved in the bad news process: patients, caregivers, surgeons, and nurses. The wider study's data collection ceased when the number of participants per group was sufficient to be analysed as a stand-alone group. The current study's small sample size aligns with the idiographic principle of IPA as detailed analyses of individuals' lived experiences could be conducted. This is considered appropriate for an IPA enquiry as the quality and depth of the accounts are given greater priority than the quantity (Eatough & Smith, 2017). The inclusion of the perspective of adult patient caregivers in the current sample attends to the under-representation of this group in the existing qualitative literature (Matthews et al., 2019).

The interviews followed a semi-structured interview schedule that was developed by the primary author and reviewed by the co-authors and an advisory group of cancer workers (established to guide the development and execution of the study; see Appendix L for the interview schedule). Interviews went for 30-80 minutes, were audio-recorded, and transcribed verbatim.

Ethical approval was granted from the Health and Disability Ethics Committee (16/NTB/164) and the hospital's ethics boards.

Analysis

Interviews were analysed following the phases of IPA outlined by Smith et al. (2009). It is recognised in IPA that findings are a result of a dual interpretation process, whereby the researcher has an active role in interpreting the participants' interpretations of their experiences, referred to as the double hermeneutic. The analysis was led by the primary author, which involved a detailed examination of one interview at a time, attending to IPA's idiographic commitment (Smith et al., 2009). The first participant's interview transcript was repeatedly read, followed by initial coding in a line-by-line fashion within the page margin to capture aspects of importance, as well as offer possible interpretations of underlying meaning. These initial codes were then integrated to develop tentative themes before the next participant's transcript became the focus. Once all interviews were individually examined, the initial codes and themes from the same linked case were compared, exploring consistencies and differences in what each participant spoke about as important when bad news was delivered. The data set was then looked at as a whole to identify superordinate and subordinate themes across the five linked cases.

As a means to increase the credibility of the findings, and to address the possible influence of the primary author's prior knowledge of the topic (conducting a meta-synthesis [Matthews et al., 2019] and interviews that were not part of the current study) and background (Clinical Psychology trainee, living outside of the study locality) on the themes identified, the themes and supporting evidence were independently reviewed by co-authors. The co-authors had over ten years' experience with providing psychological services to oncology patients in the study locality, as well as expertise in qualitative research methods. This process of review was the ensure that the findings were grounded in the data.

Results

Five linked cases were formed, each representing a different patient's case of breaking bad news (see Figure 3 for the linked case network; all names used are pseudonyms). The linked cases were made up of thirteen participants, purposively sampled: five patients, four caregivers, two surgeons, and two nurses (see Table 9 for participant demographics). Two patients who consented to a linked case were not included in the study as the caregiver or HCPs involved in the patient's case either did not respond to the invitation to participate or did not consent to participate. There were five surgeons identified by patients to be contacted as part of a linked case who did not respond to the invitation to participate. Three of the linked cases included the perspective of at least one HCP.

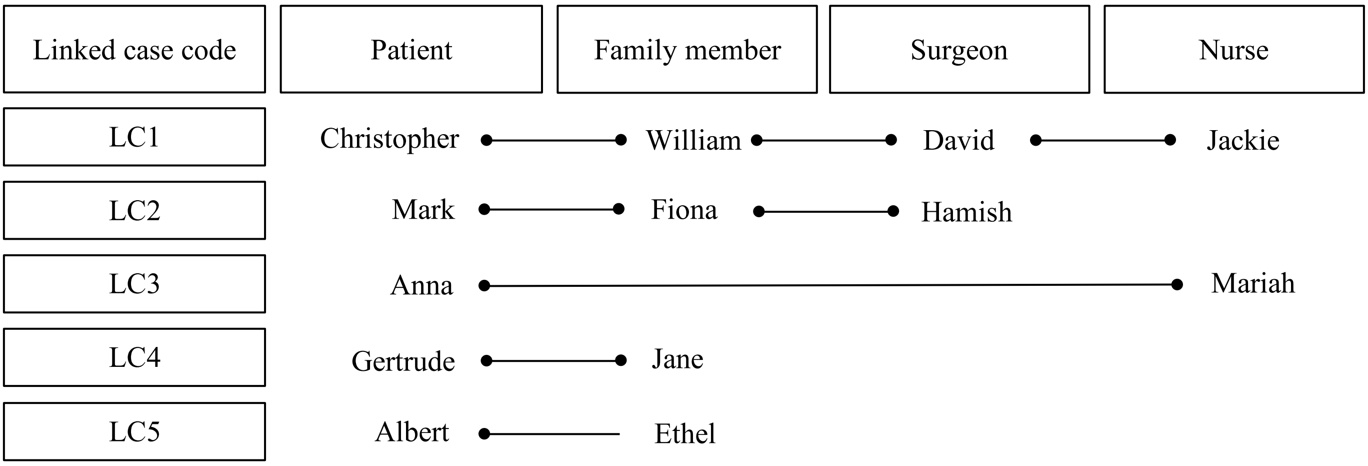

Figure 3. Linked case network. Note: All names used are pseudonyms to protect participant confidentiality.

Table 9

Participant Demographics

Participants	**Characteristic**	**n**
Patients	Age (mean [range])	60.2 [33-80]
	Sex	
	Male	3
	Female	2
	Ethnicity	
	NZ European	4
	European/Māori	1
	Cancer type	
	Prostate	2
	Bowel	2
	Breast	1
Caregivers	Age (mean [range])	55.3 [44-69]
	Sex	
	Male	1
	Female	3
	Ethnicity	
	NZ European	4
	Relationship to patient	
	Partner/spouse	3
	Child	1
Surgeons	Sex	
	Male	2
	Ethnicity	
	NZ European	1
	European	1
Nurses	Sex	
	Female	2
	Ethnicity	
	NZ European	1
	European	1

Two superordinate themes were identified among the five linked cases, labelled ‘accurately perceiving and responding to needs’ and ‘carers fulfilling necessary roles’, each with two subordinate themes (see Figure 4). These themes are described below within the linked cases (here forth denoted by the linked case (LC) code outlined in Figure 4) and supported by direct quotes.

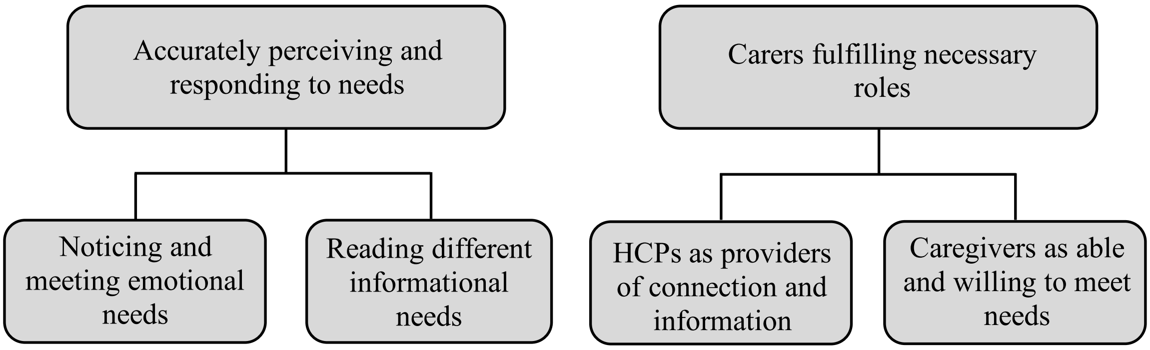

Figure 4. Illustrated coding tree of superordinate and subordinate themes. HCP= Healthcare professional.

Accurately Perceiving and Responding to Needs

During the delivery of bad news, patients and their caregivers spoke about the needs they had at the time and how these were met by those involved in their care. In linked cases that included the bad news deliverer and receiver perspective, the direct comparison highlighted the importance of HCPs recognising and attending to patients’ and caregivers’ specific emotional needs (‘noticing and meeting emotional needs’) and delivering information in the way that suited each patient (‘reading different informational needs’).

Noticing and meeting emotional needs. There were several examples within the linked cases where the patient’s need for a specific form of emotional support was accurately perceived and delivered by one of the HCPs involved in their care. This was exemplified in LC3, when the nurse, Mariah, saw the importance of giving hope to the patient, Anna. Mariah explained:

> *They were about to start having a family- that was their focus, and then to be told, "oh wait, hang on a tick." I know that she was very devastated at the*

> *thought that that might not be an option… and I just thought before we do anything, I need to give her some hope in regards to the fact that she can still have children (Nurse, LC3).*

The importance of receiving hope at that time was paralleled in the patient, Anna's, account:

> *Another huge thing that has been affected by my diagnosis is my husband and I haven't started a family yet and that's something that we really want as soon as possible. So, when Mariah told me I would be stuck on this tablet for ten years, I immediately saw my plans for children disappear before my eyes and I was very upset. Turned out she then said there will hopefully be a way for us… once Mariah said there are ways, we all felt a little better (Patient, LC3).*

LC2 provided an example of all those present in the bad news consultation accurately recognising the emotional impact the news had on the patient. The patient, Mark, described how shocked he was when he received the news of his cancer diagnosis. Mark said:

> *Straight away, you just get angry and "why's this happening to me?" Just lots of things raced through my mind (Patient, LC2).*

Mark's wife and surgeon demonstrated recognising this impact in their accounts of the consultation. His wife, Fiona, and surgeon, Hamish, recalled this in the following two extracts:

> *It was sort of like, "woah" and then I could see Mark, but it was more or less like there was nothing else there and nothing else was happening. And I just was looking at his face and it just dropped and went white (Caregiver, LC2).*

> *I do remember him being really shocked by it, his face was pretty blank (Surgeon, LC2).*

It was evident that Fiona's and Hamish's attention was on Mark at that time, which meant the emotional impact for Mark was immediately recognised and could then be attended to.

LC1 demonstrated the importance of the bad news receiver making their emotional support needs known to HCPs in order for them to provide appropriate support. The surgeon, David, explained that his general approach to breaking bad news involved noticing when the patient's support person(s) present needed support. David said:

> *So, breaking bad news is also trying to support the support person (Surgeon, LC1).*

However, the patient's partner, William, indicated that he hid his need for emotional support, despite it being present, in interactions with HCPs. William explained:

> *I did feel like sometimes that his doctors and that didn't pick up when I was down, they just sort of bypassed me, but that is probably my fault because I am very self-aware and can control my feelings (Caregiver, LC1).*

Thus, this case illustrates that while HCPs may be aware of the needs of caregivers, getting those needs met is a bi-directional interaction that also relies on caregivers revealing their needs to others.

Reading different informational needs. The linked cases also highlighted the impact of HCPs accurately perceiving the amount of information the patient needed at the time of breaking bad news, as this could vary from patient to patient. In LC3, the patient, Anna, stated that she needed more information than she was given by her General Practitioner who first broke the news to her of her cancer. Anna shared:

> *While I waited, I just thought, "I need more information. I need more. I need to know exactly what I'm dealing with here, right now" (Patient, LC3).*

When Anna met nurse, Mariah, to discuss her diagnosis and treatment further, Mariah accurately perceived that Anna was the type of patient that would benefit from being well-informed, based on the number of questions she asked during the consultation. Mariah said:

> *So, I think there was probably a lot of information given in that initial meeting but I sense that Anna is the type of person that also needs that, you know…I remember her asking a lot of questions (Nurse, LC3).*

Anna reflected positively on her consultation with Mariah; the congruence between her need for information and what was provided may have contributed to her satisfaction.

While the patient, Mark, in LC2 had different information needs to Anna, his surgeon, Hamish, also accurately perceived what his needs were at the time of sharing his diagnosis. Hamish read Mark's shocked facial expression to indicate that it would be best for him to limit the amount of information he gave Mark at that time. The surgeon, Hamish, said:

> *So, I do remember quite clearly Mark being pretty shocked with the news, so his wife was asking a lot of the questions initially. And I tried not to give too much specific information about the next steps…I was pretty confident that he wouldn't be taking much of it in at all (Surgeon, LC2).*

The accuracy of Hamish's perception was corroborated by Mark, who recalled that his emotional reaction when being told of his cancer diagnosis limited the information he could absorb and he appreciated the opportunity to have subsequent consultations. The patient, Mark, explained:

> *And they did say like you'll probably only take in half of what you hear so they get you back again for two more consultations. And then that was really good because you only took in- I was angry, bam straight away (Patient, LC2).*

These linked case comparisons of deliverer and receiver perspectives demonstrate the range of emotional and informational needs patients can have at the time of receiving bad news, and the importance of HCPs accurately recognising and responding to these needs. In one linked case, it was also highlighted the importance of those in need of support communicating this and not trying to suppress their needs. It is possible that consistency between what the receiver wanted and what the deliverer provided contributed to a more satisfactory breaking bad news experience for these patients and their caregivers.

Carers Fulfilling Necessary Roles

The linked cases revealed a variety of roles taken on by HCPs and patients' caregivers during the breaking bad news process to meet the needs of the patient. For HCPs, their roles involved covering the patient's need for information and a personal connection ('HCPs as providers of connection and information'). Within patient-caregiver dyads, successful caregiver roles arose from the resources caregivers had to offer aligning with the needs of the patient ('caregivers as able and willing to meet needs').

HCPs as providers of connection and information. It was evident that receiving information and establishing an interpersonal connection were important aspects of a patient's interaction with the HCP team at the time bad news was broken; these roles were understood to be fulfilled by the surgeon and nurse, respectively. This was illustrated in LC3, when nurse, Mariah, provided an account of her role as being focused on relationship building when she first meets the patient (Extract 1) and the surgeon's role as focusing on giving information about the next steps of treatment (Extract 2). Mariah explained:

> *I am hoping that's the time when I start to establish a relationship and it's really hard when you've just heard some bad news to actually link with somebody. Like they're still processing what is being said and then I'm in there saying, "ah this is who I am and this is what I do." But if anything, I hope that people can go home knowing that I will always be there for them (Extract 1; Nurse, LC3).*
>
> *[The surgeon's] really good at when he explains things, but he can sometimes just shut off and say, "right, it is what it is and now we have to deal with it." Like he almost loses his- it's not that he's lost his empathy 'cos he's not like that, but he just kind of gets into this, "right, you know, this is what we are dealing with, now we've got to sort this," you know. And he gets quite um not so emotive in his responses. It's all very black and white about what we need to do, yeah (Extract 2; Nurse, LC3).*

The patient in LC3, Anna, recalled her nurse and surgeon fulfilling the roles in a congruent way with how the nurse, Mariah, described them. Anna saw Mariah as being approachable and warm (Extract 1) and her surgeon being focused on providing a plan for treatment (Extract 2):

> *[Mariah] just had such a lovely, warm personality; you feel like you can just ask her anything and you never feel like any question is a stupid question" (Extract 1; Patient, LC3).*
>
> *So, they pretty much said that the next step would be the mastectomy and the surgeon said, "it's usually within two weeks." But then he said, "I can actually get you in this Friday if you feel you are up to it." And I said, "yip, the quicker the better as far as I'm concerned" (Extract 2; Patient, LC3).*

Anna spoke about having had a positive experience in her interactions with Mariah and her surgeon, possibly contributed to by her need for information and interpersonal connection being effectively fulfilled by someone in the HCP team.

LC1 provided another example of the deliverers and receivers of bad news having a congruent understanding of HCPs' informational and relational roles. The surgeon in LC1, David, viewed his role as providing information, indicated when he described breaking bad news as an *"information process" (Surgeon, LC1).* The patient's partner, William, explained that this was what he expected from the surgeon and was satisfied that he focused on delivering information:

> *Upfront, with all the facts, yeah… that was how it was done" (Caregiver, LC1).*

Alternatively, William reflected on appreciating the personal relationships he formed with the nursing staff. He recalled:

> *Yeah, but we had different nurses in the follow-up appointments after that and they were absolutely brilliant. Couldn't, couldn't do enough…by the time we went in for the second or third time, it was, you know, no PC, just a hug and a hello and - real people-people (Caregiver, LC1).*

The nurse in LC1, Jackie, understood her role as being focused on forming an interpersonal connection, congruent with William's understanding of a nurses role. She said:

> *Yeah, and you get that rapport with them and that is probably the best part of this radical prostatectomy pathway" (Nurse, LC1).*

For William, having his information and relational needs met by the surgeon and nurse (respectively) meant that, together, he received a complete package of care in the way he expected, which may have contributed to his satisfactory experience of the breaking bad news process.

Congruent with the common understanding that surgeons are the information providers, the surgeon, Hamish, in LC2 focused on how he transmitted information to the patient, Mark, when describing his role during the breaking bad news process. Hamish said:

> *I went through a book from a pack that we give every man diagnosed with prostate cancer about exactly what his was and what the options were" (Surgeon, LC2).*

However, for the patient, Mark, he recalled the relationship he formed with his surgeon, Hamish, as the most memorable part of his interaction with him when he was told bad news. Mark said:

> *I kept thinking, "who's this young guy? He's younger than me." And he was sort of smartly dressed and I was thinking, "oh yeah." This is my thoughts, "oh yeah, what would he know, he looks too young." But the moment he started talking to me, and then- how did we strike it up? He started asking about some of my things and what I do, and I said, "I help out with Sunday school kids" and stuff like that. And he said, "ah what church do you go to? I go to one in [city]." And I went, "aw yeah, you're my doctor." Straight away, bang, that was my feeling, my gut feeling, my heart feeling "you're my doctor." And then I lost that whole thing of him being younger and all the rest of it" (Patient, LC2).*

LC2 indicates that a HCP can fulfil both the roles of being an information provider and forming a personal connection. During their interview, Mark and his wife, Fiona, placed less emphasis on the role of the nurses in their care, possibly since their surgeon fulfilled the relationship-building role that a nurse would have typically filled. It may have also been that the relationship Mark and Hamish formed helped to smooth the way for easier delivery of information about Mark's cancer diagnosis.

Caregivers as able and willing to meet needs. Direct comparisons of patient and caregiver perspectives highlighted that families drew on their resources and capabilities to fulfil roles that successfully met the needs of patients when they received bad news. This was demonstrated in two ways.

Firstly, caregivers fulfilled the role of being patients' primary caregivers. This can be seen in LC4 when the patient, Gertrude, spoke about her daughters moving into the role of being the 'mother', a position she usually held when not faced with illness. Gertrude explained:

> *Um almost like a motherly role, [my daughters] took over being the mother to like look after me to make sure I had everything I needed and they'd brush my hair and, you know" (Patient, LC4).*

Gertrude's daughter, Jane, understood that she held a primary caregiver role, illustrated when Jane spoke about ensuring she was present during ward rounds and involved in her mother's care. Jane said:

> *Because of [doctor] misdiagnosing Mum we- yeah, my sister was quite angry about that. It just- I mean it wouldn't have made a difference to the outcome, but it would have made a difference for how long Mum was in pain for. Yeah, so we wanted to make sure we heard what they had to say and or what we could do or whatever (Caregiver, LC4).*

Gertrude likely needed someone in the family to take on the primary caregiver role when she was diagnosed with cancer and Jane was willing and able to move into this position. This suggested that this family unit had the resources to meet this need for the patient.

Secondly, caregivers could take on the role of being the holder of information on behalf of the patient. This was seen in LC5, when the patient, Albert, and his partner, Ethel, were offered written information about Albert's diagnosis and Ethel was the first to read and realise what this meant. Ethel said:

> *And [the nurse] gave us a lot of information in a folder and I was quickly looking at it and thinking, "oh my God." So, I think I just went into shock (Caregiver, LC5).*

In the interview for LC5, it became apparent that the patient, Albert, viewed Ethel as being in the information holder role, indicated when he looked to her to explain details about his cancer:

> *Ethel: "And yours was stage 3 at that point.*
>
> *Albert: Was it?*
>
> *Ethel: Yeah.*
>
> *Albert: What does that mean?*
>
> *Ethel: [If it gets to] stage 4- that's it." (Caregiver; patient, LC5)*

Ethel likely fulfilled Albert's need for someone to receive and remember information related to his illness. It also suggests that being the holder of information may come with an emotional toll that would be prudent for HCPs to consider.

These linked cases highlighted that HCPs and caregivers fulfilled various roles to meet the needs patients had at the time of receiving bad news. For HCPs, it appeared that the receivers of bad news were satisfied if their need for information and an interpersonal connection was fulfilled, be it by different members of the HCPs team or the same HCP. For the roles taken on by caregivers, these were successful when the caregiver's resources were congruent with the patient's needs.

Discussion

The current study aimed to closely examine and directly compare the perspectives of all those involved in a series of single-patient cases ('linked cases') on aspects of importance during the breaking bad news process. These within-case comparisons illustrated that the receivers of bad news had a range of needs at that time and benefitted when these were accurately perceived and attended to by HCPs. The linked cases also illustrated that patients desire both information about their cancer and a personal connection, and these roles can be satisfactorily fulfilled by different members of the HCP team or by one HCP. Caregivers could also satisfactorily meet patients' need for primary caregiving and information gathering when they had the resources to do so.

The linked cases highlighted the centrality of HCPs utilising interpersonal skills to meet patients' various emotional and informational needs. HCPs in the current study established the needs of patients through taking time to find out the patient's priorities, attending to the questions they asked, and responding to cues from their facial expressions. These attending behaviours led HCPs to accurately perceive what emotional support was needed and the amount of information to share. Consistent with this finding, Bousquet et al. (2015) reported that oncologists identified how key assessing a patient's individual needs were when bad news was delivered, basing this on careful listening, their 'intuition', and the questions patients asked them. This suggests the value of HCPs developing interpersonal skills to attend to patients' verbal and non-verbal cues to accurately respond to their emotional and informational needs when bad news is delivered.

The current findings illustrated that HCPs attending to patients' needs can be complicated by the receiver of bad news not making their needs apparent to HCPs. This was the case for one caregiver in the study. Previous qualitative studies have reported that patient caregivers can suppress their emotional expression in fear of appearing weak in their supporter role (Matthews et al., 2019), which could lead caregivers to not disclose when they have emotional needs that require attending to. This suggests that while HCPs have an active role in perceiving patients' verbal and non-verbal cues when assessing their needs, caregivers also have a responsibility to communicate their needs. Creating a communication context that allows caregivers to feel comfortable disclosing their needs may be a necessary pre-condition for this to occur.

The linked cases in the current study highlighted that different HCPs can work together to satisfactorily meet the information and relational needs of patients and caregivers, suggesting that the onus was not on one HCP to meet all of a patient's needs. Taking a team approach is supported by literature that recognises that, while doctors are typically tasked with breaking the bad news, nurses and allied HCPs (e.g., psychologists and social workers) have a crucial role in supporting patients (Abazari et al., 2016; Butow et al., 2002; Oikonomidou et al., 2017). Nurses took an important role in providing emotional support to patients in the current study, lending further confidence in this finding in the existing literature. When HCPs who provide information also formed a personal connection with the patient, as illustrated in one linked case, this relationship may facilitate a smoother sharing of difficult information.

The linked cases also demonstrated that caregivers fulfil important roles such as primary caregiving and gathering information, aligning with studies that have reported family as playing a pivotal role in the process of breaking bad news (Datta et al., 2017). Guidelines for involving family members in difficult conversations have recently been suggested in the literature (Laidsaar-Powell et al., 2018). The current findings support the explicit recognition and involvement of the caregivers in bad news discussions to support patients; however, caregivers must have the resources to offer this support and do so in a manner that meets the patient’s needs. While this was the case for the limited number of patient-caregiver dyads in the current study, this may not always be the reality.

Study Limitations

The linked case study design enabled the direct comparison of the experiences of the patient, caregivers, surgeon, and nurse involved in a single patient’s case of breaking bad news, exploring aspects of importance from various perspectives. This can be seen as a process of triangulation and strengthens the comprehensiveness of the findings drawn from this study (Larkin et al., 2019; Mays & Pope, 2000). However, only one of the linked cases was complete (i.e., patient, caregiver, surgeon, and nurse) and two of the linked cases did not include the perspectives of a HCP. The completeness of the linked cases was influenced by the challenges faced with the recruitment of HCPs for linked cases, which may have been driven by limitations of the recruitment strategy or competing demands of HCPs’ busy workloads. Refinement of the recruitment strategy through means such as enhancing commitment in the conducting of the study from staff at all levels of the organisation and greater visibility of the study within the study locality may be beneficial for future applications of the linked case design that involved HCPs. While the small sample size was considered appropriate from a methodological standpoint (Smith et al., 2009), the completeness of the linked cases is an important contextualising variable when considering the broader applicability of the findings.

The context in which the data was collected also warrants consideration. Interviews occurred four to eleven months after the patient’s surgery, representing a delay between the delivery of bad news and when the interviews were conducted. While patients and their caregivers appeared to be able to recall the specific details of receiving bad news, the surgeons and nurses had some difficulty. The length of the time may have limited the depth and accuracy of the details HCPs were able to recall, given the high volume of patients they encounter. Additionally, two patients and their caregivers chose to be interviewed together, which may have influenced how congruent their experiences were reported to be in this study. Furthermore, there is a potential for a participation bias whereby the patients who agreed to participate may have had better rapport with HCPs and the HCPs who agreed to participate may have been more attentive to patients' needs. While the recruitment was not limited to patients with successful surgical treatment outcomes, this was the case for all the patients in the study, and possibly influenced how each party reflected on the time when bad news was broken. Once again, these present as important contextualising variables when considering the applicability of the findings.

The current study was limited to surgeons and nurses that deliver cancer-related bad news. The literature reports the valuable role that allied HCPs can play in the breaking bad news process, especially as patients adjust to the reality of their illness (Butow et al., 2002; Oikonomidou et al., 2017). As the process of breaking bad news has aspects of significance in the lead-up, actual delivery, and aftermath (Matthews et al., 2019), future studies applying the linked case design longitudinally with interviews at multiple time points may capture the involvement of various HCPs as the patient makes sense of their bad news and the implications.

Clinical implications

The emphasis on interpersonal skills in the current findings suggests this as a key aspect when training HCPs to effectively deliver bad news. The variation in the needs of individual patients across the linked cases points to supporting HCPs to develop skills in assessing the needs of each patient and adjusting their delivery and response accordingly, which the HCPs in our small sample appeared to do accurately. HCPs are encouraged to access training programmes that include interpersonal skills in eliciting, attending to, and responding to patients' individual needs in the context of bad news disclosure. To support HCPs in accurately identifying the needs of those they are breaking bad news to, HCPs should encourage caregivers to make their needs known.

Once the patient's needs are accurately identified, the current findings suggest that HCPs do not have to fulfil the patient's informational and relational needs on their own, unless they have the capacity to do so. If, for example, a surgeon is aware that their skill set lies in transmitting clinical information and their time is limited, two linked cases indicated that the receivers of bad news can find it acceptable for a nurse to be the one they form a personal relationship with, and indeed, this may be the roles they expect each to fulfil. What appeared important in the current study was that the patient's need for both information and personal connection were attended to by someone within the HCP team. It is recommended that HCPs reflect on their strengths and available resources (e.g., time) and recruit other members of the team to support them to provide a complete package of care for patients and their caregivers.

The current findings also suggest that caregivers can successfully fulfil important support roles for patients when there is congruence between the patient's needs and the resources the caregiver can offer. In practice, it is recommended that HCPs assess the capabilities and resources of caregivers to provide support while upholding the patient's autonomy to decide how their caregivers are involved.

Conclusions (*Part Two* Summary)

Patients and caregivers have a range of emotional and informational needs when bad news is delivered about cancer. They can benefit from HCPs accurately perceiving and responding to these needs and fulfilling the roles of the information provider and relationship developer within the HCP team. Caregivers can also meet the patient's needs during the bad news process by utilising their resources and capabilities. These findings recommend that HCPs develop and utilise interpersonal skills, work as a team, and draw on patients' caregivers to support patients when breaking bad news.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

This final chapter begins by offering a brief overview of the study and key findings from the participant group- and linked case-based analyses, before outlining four conclusions that can be drawn across the research in its entirety. The conclusions will be followed by recommendations for how the process of breaking bad news can be improved in the future within the surgical departments of MidCentral District Health Board (MDHB), attending to the third objective of the study. Key considerations for the study outcomes, including strengths and limitations, will then be outlined, along with suggestions for future research and the contributions the study has made to the literature.

Study Overview

The current study aimed to explore the experiences of patients and their family/whānau members receiving, and surgeons and nurses delivering, bad news about cancer within the surgical departments of MDHB. To achieve this, semi-structured interviews were conducted with patients, patients' family members, surgeons, and nurses and analysed using an interpretative phenomenological approach. The data were analysed in two ways: by group (*Part One* of Chapter Five) and by linked case (*Part Two* of Chapter Five).

Group-based analysis. The perspectives of ten patients, six family members, five surgeons, and six nurses, provided insight into the numerous aspects that each group considered important and had to navigate when bad news is broken.

For patients, this included: their prior beliefs and expectations they brought to the bad news encounter; the importance of establishing a personal connection with HCPs and feeling valued; offering concern and compassion to those caring for them; requiring support tailored to their needs in order to cope with hearing bad news; and the ongoing shift in perspective and priorities brought about by receiving bad news about cancer and having successful treatment. As such, patients spoke about the receiving bad news process as encompassing what they brought to the encounter, the experience during the exchange, what they needed following receiving bad news, and the enduring impact this news had on their lives.

For family/whānau members, the important aspects they recalled included: their strong desire to protect the patient, advocate for them, and place them at the centre of the care offered. In addition, they described recognising that they, themselves, needed support to cope with the news and the challenges of being a supporter that was tailored to their coping style. Thus, the focus of their accounts was on both providing care and receiving support.

For HCPs, delivering bad news required: navigating the variability in patients' situations and how each HCP approached the task; operating under organisational constraints of limited time, unsuitable environments and high workloads; the need to attend to patients' psychological wellbeing as well as their medical needs; having to work as a team with other HCPs and family members in order to meet patients' various needs; and recognising the emotional toll this task took, leading to the necessity of finding ways of coping to keep doing this part of their job. Therefore, HCPs conceptualised breaking bad news as being both a professional challenging, and personally impactful, task.

This group-based analysis provided useful insights into how the process is experienced from the perspective of being a patient, a patient's family/whānau member, and a HCP. While each person experienced the breaking bad news process through a different lens, they all spoke about the challenges they faced, the different roles people took, their understanding of the impact the process had on others involved, and their individual needs during that time.

Linked case-based analysis. The close examination of five linked cases enabled the perspectives of those involved in a single patient's case of breaking bad news to be directly compared. This way of analysing the data revealed that the receivers of bad news had different emotional and information needs at that time, and benefitted from HCPs accurately perceiving and responding to their individual needs. The analysis also demonstrated that it was acceptable to the receiver of bad news if the same, or two different, HCPs fulfil their needs for information and an interpersonal connection when bad news was delivered. Family members also fulfilled different roles based on their capabilities and resources and what met patients' needs. Overall, the findings highlighted that the receivers of bad news have a range of needs, and it is important that the providers of care and support are able to accurately perceive and respond to these by taking up roles that fit with their resources, and meet the needs of the patient.

Conclusions

Examining the findings across the group- and linked case-based analyses enabled four main conclusions to be drawn from this study about the process of breaking bad news. These were labelled ‘no two alike’, ‘building relationships’, ‘a challenge for all’, and ‘shared responsibility’. There was some cross-over in the findings that support these conclusions; thus, the subordinate themes that contributed will be noted in brackets within the description. Rather than being a set of prescribed steps or list of dos and do not’s for HCPs breaking bad news, these conclusions are offered as a set of overarching principles for how this complex process can be understood and suggestions of how this task could be approached.

Conclusion one: No two alike. A consistent finding across the accounts of patients, family members and HCPs was that breaking bad news was synonymous with variability: no two instances of delivering bad news were the same, nor would one approach to delivery or coping suit all patients and situations. The variation was evident in the group-based analysis when patients’ health beliefs impacted their reaction to being diagnosed (‘why me?’) and expectations of care informed what the patient considered ‘bad news’ to be (‘unmet expectations of care’). HCPs were aware of how variable the settings, care pathways and patient reactions can be (‘navigating variability and unpredictability’) and the need to tailor their approach to match the needs of the receiver (‘the art of the tailored delivery’). HCPs also recognised that each of their approaches to delivering bad news varied, as this was informed by who they are as people (‘delivery style reflects the deliverer’) and the experience they had had in delivering bad news (‘experience as the teacher’).

The group-based analysis also illustrated the variation in the way each involved party coped with the challenges of breaking bad news. This was evident for patients (‘coping matching needs and beliefs’) and family members (‘matching support to individual needs’), requiring an individual approach to meeting their needs for support. Similarly, HCPs differed in the strategies they used to cope with this challenging part of their job to support their emotional wellbeing and longevity in their career (‘coping to enable longevity’).

The linked case analysis reiterated that patients and family members can have various needs in regards to emotional care ('noticing and meeting emotional needs') and the amount of information they benefit from knowing ('reading different informational needs'). This analysis demonstrated how appreciative patients and family members are when their specific needs are recognised and attended to by HCPs.

Implications. The variation between each instance of breaking bad news and how individuals coped with the process suggests that a one-size-fits-all approach will not suffice; rather, breaking bad news needs to be approached with flexibility. This proposes a shift in mindset from focusing on predicting what will be the 'right' or 'wrong' way to break bad news for all patients, to building HCPs' skills and confidence in assessing and attending to a bad news recipients' individual needs during the consultation. Patients' and family members' various support needs, and appreciation of these being attended to, imply the importance of HCPs tailoring their delivery approach and support provided accordingly. HCPs' ability to do this may better equip them to navigate the inevitable variability they face when breaking bad news and the possibility of a more satisfactory experience for those receiving the news.

The role of experience in shaping a HCP's individual approach to breaking bad news suggests that exposure to various breaking bad news scenarios early on in training (i.e., in an observational role, initially) may be beneficial to HCPs as part of their training. This may mean that HCPs rely less on trial-and-error when in practice. The influence of person-based variables in how HCPs develop their approach to breaking bad news suggests there may also be a role for engaging in self-reflection and supervision to identify areas for improvement. These processes may also assist HCPs to identify the personal challenges they face with breaking bad news and seek support in a way that aligns with their style of coping.

Conclusion two: Building relationships. The importance placed on interpersonal variables in the findings established HCP-patient relationships as a core part of the breaking bad news process. This was evident in the group-based analysis when patients spoke about valuing having formed a personal rapport with the HCPs providing their care ('valuing a personal connection') and sensing that they were genuinely cared for and not just another medical case ('see me as a person'). HCPs were aware of the importance of relationship-building when they expressed that nurses were often tasked with providing emotional support to the patient as part of the care package provided by the HCP team, forming a more personal relationship with the patient (‘doctor as deliverer, nurse as supporter’). Additionally, the existence of a relationship was part of the rationale for trialling one of the nurses taking on the role of breaking bad news. Furthermore, HCPs expressed dissatisfaction that systemic factors hindered their ability to provide ongoing care to their patients (‘time as a scarce resource’, ‘valuing providing ongoing emotional care’); and that their workload demands compromised the empathy they could bring to the HCP-patient interactions (‘workload demands erode empathy’).

The linked case analysis demonstrated that forming a patient-HCP relationship, along with providing information, was one of the key roles a HCP fulfilled during the breaking bad news process (‘HCPs as providers of connection and information’). Patients were satisfied if the interpersonal connection was attended to by the same, or another, member of the HCP team that provided their diagnostic and treatment information. If the information deliverer also developed a relationship with the patient, this may help facilitate an easier delivery of difficult information.

Implications. This finding suggests that forming relationships is central to the process of delivering bad news, rather than an optional extra. There was congruence between the patients’ desire for a personal connection and how important HCPs viewed relationship-building, suggesting that both the deliverers and receivers of bad news see this as a priority. It is possible that the benefits of enabling training and resources to support the interpersonal aspect of the bad news interactions could be two-fold: providing patients and family members with a feeling of being valued and cared for, and affording HCPs a feeling that they have delivered healthcare in the way that aligns with their values. As such, it may be that all those involved would benefit. The acceptability of a personal connection coming from someone within the HCP team suggested that when resources are scarce and workload demands high, satisfactory interpersonal care can be provided by HCPs working as a team.

Conclusion three: A challenge for all. The current findings clearly established that breaking bad news about cancer is a challenging process for all those involved, whether being the receiver or deliverer of the news. This was evident in the group-based analysis when patients, family members, and HCPs recognised the impact the process of breaking bad news had on them personally. Patients spoke about the challenge arising from the close association of cancer and death (‘cancer means death’) and requiring support from numerous sources to cope with receiving the news and the implications thereof (‘needing support from multiple sources’). Family members spoke about the challenges inherent in being a supporter and appreciating when they were given support by HCPs, friends, colleagues and employers (‘supporters require support too’). The challenge of this task for HCPs was evident in the emotional toll this part of their job could take (‘HCPs as human too’, ‘coping to enable longevity’), and not being able to deliver healthcare in a way that aligned with their values due to organisational constraints (‘time as a scarce resource’, ‘limitations of an unsuitable environment’, ‘workload demands erode empathy’).

The group-based findings also demonstrated that each party recognised how challenging this process could be for the others involved. This was evident when patients expressed concern for their family members who were present when the bad news was delivered (‘bad news takes a toll on family’) and compassion for how challenging this role must be for HCPs (‘compassion for HCPs’). Family members demonstrated their concern for the patient’s vulnerability when focussing on the patient during the bad news consultation (‘all attention on the patient’), and wanting to protect the patient (‘being a patient protector’) and advocate for them to get the best care (‘advocating for the patient’). HCPs demonstrated knowing the challenges of this process for patients by recognising the patient’s need for psychological support during the bad news consultation (‘reducing the emotional burden’) and on an ongoing basis, even if organisational demands constrained this (‘valuing providing ongoing emotional care).

The linked case analysis contributed to the understanding of the challenges of the breaking bad news process by demonstrating that patients and family members have emotional needs and benefit from HCPs recognising and attending to these (‘emotional needs’). This analysis also highlighted that, while HCPs might have the intention to offer support to family members, this process can be complicated by family members not making their support needs known.

Implications. The challenge of the breaking bad news process for all those involved suggests that it is important that patients, their family members, and HCPs receive support during and following this process. Patients and family members appear to appreciate having multiple sources of support from those present in, and outside of, the bad news interaction. This suggests the importance of connecting the receivers of bad news with a wide support network. The personal impact of the task itself (and the constraints HCPs have to work under) suggests that organisations have an important role in prioritising supporting HCPs' emotional wellbeing and adequately resourcing their services.

While it is likely unavoidable that bad news about cancer will have an emotional impact on patients and their family members, adequate support may lessen the intensity or duration of the emotional burden. It may also be that when family members are supported (facilitated by them making their support needs known), they may be better able to support their loved ones. Additionally, if HCPs are supported to manage the emotional impact of this task and have fewer organisational constraints impacting the care they can provide, they may be able to break bad news in a more satisfactory way for patients and family members, and experience greater job satisfaction as a result.

The stance of concern and compassion taken by each party towards the others involved suggests that patients, family members, and HCPs can see beyond the impact bad news has on themselves. The ability to do this may help HCPs to deliver bad news to patients and family members with empathy for the gravity of hearing bad news about cancer. For patients and family members, this may facilitate greater acceptance and understanding for the organisational and personal challenges HCPs have to navigate in carrying out this difficult part of their job.

Conclusion four: Shared responsibility. The findings highlighted that, for the breaking bad news to go as well as possible for all those involved, there is shared responsibility among different individuals and the healthcare organisation. It was evident that there needed to be many individuals involved to support those delivering and receiving the news. This was seen in the group-based analysis when patients and family members spoke about benefitting from having a network of support to cope with the outcome of receiving bad news ('needing support from multiple sources', ‘supporter require support too’). HCPs also understood the need to have multiple people involved when they spoke about taking clear roles whilst working as a team to break bad news (‘doctor as deliverer, nurse as supporter’). The linked case analysis demonstrated that patients have a satisfactory experience when surgeons and nurses share the responsibility to fulfil informational and relational roles (‘HCPs as providers of connection and information’).

The findings also demonstrated that family members can be drawn on as a resource to support the patient, sharing some of the patient care responsibility. HCPs spoke about family members helping with getting important information across to the patient that is communicated in the bad news consultation (‘family as a resource’). However, when family are involved, this must be in a way that meets patients’ needs (‘caregivers as able and willing to meet needs’) and upholds their autonomy (‘supporting patient autonomy’).

There was an important role for healthcare organisations in supporting HCPs in breaking bad news in the best way possible. This was evident when HCPs expressed the compromises they had to make to their practice as a result of the unsuitable physical environment they had to work in (‘limitations of an unsuitable environment’) and the high demands on their time and workloads (‘time as a scarce resource’, ‘workload demands erode empathy’). Patients also spoke about perceiving their wait times for surgery as indicative of how personally valued and cared for they felt by HCPs (‘see me as a person’). This pointed to the impact of resource limitations in healthcare organisations on patients and how this can negatively impact their relationship with their HCPs.

Implications. The role that different individuals and the healthcare organisation have in the breaking bad news process suggests that the responsibility does not fall on an individual to make breaking bad news go as well as possible. HCPs working as a team suggests the importance of open discussions among HCPs about their personal strengths (e.g., interpersonal skills, information delivery) and resource availability (e.g., time), and exploring what family members can offer that will help meet the needs of the patient. It is possible that a sharing of responsibility, alongside healthcare organisations improving workload management and resourcing, will improve the experience of patients receiving bad news by having their various needs better met. There may also be a reduction in some of the demands HCPs experience when carrying out this task, support their emotional wellbeing, and help them feel they are delivering patient care in the way they desire.

Patients' and family members' appreciation of multiple sources of support implies that the onus is not on one support provider during this difficult time. This suggests the value of establishing a support network for those who have received bad news. Due to the challenges that family members can face when providing ongoing support to their loved ones as they navigate the implications of their bad news, it may be that sharing the responsibility to support patients amongst a network will enhance family members' wellbeing and effectiveness in their support roles.

Summary of Conclusions

Across the study findings, there were four conclusions evident about the process of breaking bad news to patients with cancer within MDHB surgical departments: 'no two alike', 'relationship building', 'a challenge for all', and 'shared responsibility'. These conclusions establish breaking bad news as a complex process for all parties involved. This was seen in the variability of each instance of breaking bad news; the importance of relationship-building in the context of multiple demands; the need for all to have support during this challenging process in a manner tailored to their needs and style of coping; and navigating the shared responsibility among HCPs, family members, community cancer support services, patients' social networks, employers, and healthcare organisations to provide a complete package of care and enable the bad news process to go as well as possible. Breaking bad news is, indeed, a dynamic process that requires a multi-faceted approach to match its complexity. Suggestions for how this could be achieved are outlined in the next section.

Recommendations for Practice

The four conclusions drawn from the study findings provide the basis for numerous recommendations that can be made about the process of breaking bad news in the future. These have been organised into a series of practice aspirations, along with whom can contribute to achieving each recommendation (i.e., individual HCPs, training providers, or healthcare organisations). This is presented in Table 10.

It is important to hold in mind that these recommendations are based on a small sample of patients, family members, surgeons, and nurses involved in breaking bad news to those receiving a particular cancer treatment from a specific District Health Board (DHB) in New Zealand. As such, the recommendations are specifically applicable to the issues faced by this group, and other DHBs and departments may have different experiences. Further research could explore the applicability in other healthcare areas and settings.

Table 10

Recommendations for Practice

Practice aspiration	**Recommendation**	**Contributing party**
Take a tailored approach	Apply a set of communication principles for breaking bad news that can be flexibly applied to various situations.	Training providers; HCPs
	Attend to patients' and family members' verbal and non-verbal cues.	Training providers; HCPs
	Regularly seek feedback on the approach taken during the consultation (e.g., asking, how are you doing at the moment?)	Training providers; HCPs
	Directly enquire about what helps each patient and individual family members to cope (e.g., asking, when you had a difficult experience in the past, what helped you to manage?)	Training providers; HCPs
Build a relationship	Use interpersonal skills to form a rapport with the patient and their family/whānau members as a key part of the bad news interaction. This could be guided by the Māori cultural principle of whakawhanaungatanga.[7]	Training providers; HCPs
	Decide in advance what is comfortable and appropriate to personally disclose to patients as part of forming rapport.	HCPs
	Provide a physical environment that is private, quiet and can accommodate large groups, consulting with those who break bad news and healthcare consumers on what is needed for best care.	Organisations
	Access greater resources to reduce workload demands to enable time to form relationships and express empathy.	Organisations
Open up communication	Have open discussions within the team about resource availability and limitations and how this will be managed when breaking bad news.	HCPs
	Discuss openly with patients and family members if there are shortcomings in the process, acknowledging the impact this may have had on them.	HCPs
	Clearly communicate the rationale for patients' treatment pathways (e.g., if there is a surgery wait time).	HCPs
	Facilitate a process of feedback between HCPs and healthcare organisations to improve processes and resources.	Organisations

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[7] See Lacey, Huria, Beckert, Gilles, and Pitama (2011) for a suggested process to follow.

Collaborate	HCPs to work together as a team to fulfil relational and informational roles when breaking bad news, especially when HCPs have limited time.	HCPs; organisations
	Enquire about family members resources and skills and consult with the patient about the roles they would like family to take (e.g., the way family are involved in the process).	HCPs
Facilitate access to support	Offer support to patients and family members as standard practice.	HCPs; organisations
	Encourage family members to make their support needs known.	HCPs
	Provide information on services available and tips on establishing a support network amongst friends, the community, and employers.	HCPs
	Have adequate time for breaking bad news appointments so support can be offered within the consultation, as well as provision for follow-up appointments to be arranged if needed.	Organisations
Be self-reflective	Provide HCPs with the option of professional supervision to help facilitate a self-reflective process. This could be individual- or group-based.[8]	Organisations
	HCPs to use skills of self-reflection to reflect on their approach to breaking bad news, identifying personal strengths and areas for improvement.	HCPs; training providers
	Acknowledge the challenging aspects of breaking bad news (e.g., through peer support among members of the HCP team or supervision) and individual support needs.	HCPs; organisation
Attend to self-care	HCPs being able to access support in the way that suits their coping style.	HCPs; organisation
	Understand that HCPs need to show empathy and humanity when breaking bad news, but also sufficiently protect themselves from possible burn-out. This could be facilitated by setting appropriate boundaries between their work and personal lives.	HCPs; organisation

HCPs= Healthcare professionals

Key Considerations for Study Outcomes

The strengths and limitations specific to the linked case study design have been discussed within the second manuscript of this thesis, and will not be repeated here (see *Part Two* of Chapter Five). However, some of the considerations raised require discussion in relation to the study as a whole, and further aspects warrant reflection. These key considerations have been organised into the areas of study design, participant sample, and interview process, and will be outlined along with suggestions for future research.

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[8] Berney and Bourquin (2019) report on the use of supervision to support reflexive practice when teaching undergraduate medical students how to break bad news.

Study design. The current study developed and utilised a 'linked case' study design and, to my knowledge, it was the first time a study design of this nature had been used in combination with a more standard group-based qualitative analysis. The two forms of analyses complemented each other to strengthen the conclusions made about areas of importance for breaking bad news. This was demonstrated when the group-based analysis identified that patients and family members had individual needs, and the linked-case analysis was able to provide evidence that when HCPs accurately identified and attended to these, this was appreciated. Additionally, the group-based analysis identified that HCPs viewed bad news as a team-based task, with specific roles for surgeons and nurses. The linked case analysis demonstrated that patients were satisfied when HCPs took a team-based approach, as long as their information and relational needs were met.

The value of the group-based analysis was seen when the linked case findings did not highlight the impact that the process of breaking bad news had on HCPs. As such, it was valuable having the group-based analysis to enable the challenges that HCPs face, personally and professionally, to come to the fore.

Additionally, the conclusions drawn from the study as a whole were strengthened by a study design that enabled a process of triangulation (Larkin et al., 2019; Mays & Pope, 2000). The study included and compared various perspectives on the breaking bad news process across different groups (i.e., patients, their family members, surgeons, and nurses) and across different parties involved in the same patient's case of breaking bad news (i.e., linked cases). The strengths of the combined analyses suggest that future research into processes that involve multiple parties, both within and outside of healthcare, would benefit from a combination of group- and linked case-based analyses to increase the comprehensiveness of the findings.

Participant sample. There were several important considerations in regards to the characteristics of the participant sample. Firstly, participant interviews occurred four to eleven months after patients had their surgical procedure as part of their cancer treatment. While the rationale for interviewing patients at least three-months after their surgery was for participant welfare reasons to minimise harm at a time of potential vulnerability, the time delay may have limited the depth and accuracy of the information recalled. Patients and their caregivers appeared to be able to recall the specific details of receiving bad news; however, the surgeons and nurses had some difficulty, possibly given the high volume of patients they encounter.

Secondly, all the patients in the study had had successful cancer treatment at the time they were interviewed. This variable may have influenced the way patients, family members and HCPs reflected on their breaking bad news experiences, possibly reflecting on the process more favourably. The importance of the treatment outcome was outlined by a patient's wife:

> *Well, he could have been gone, just like that. It could have been- okay, we got bad news, but it wasn't a bad outcome, yeah (Fiona, family member).*

The inclusion criteria required participants who were in a position to reflect on their bad news experiences. Patients with poor prognoses and their families may have been at risk of being exposed to undue stress by participating, and thus, those with successful treatment outcomes could have been more likely to meet the recruitment criteria and be participants.

Thirdly, all the surgeons in the sample were male and all the nurses were female. This possibly reflects how gendered these two professions traditionally are and may have influenced the way each group reflected on aspects of breaking bad news. One of the surgeons suggested this might be the case in regards to the way each group coped:

> *I think it is changing in medicine, but the classic difference in the olden days between nurses and doctors, nurses would talk about, mainly women, they would talk about all the bad things on the ward and then in the evening they all went home and be talking about what happened in the day, maybe they would go get drinks or whatever. Whereas the doctors all go off individually, they just carry the weight. I think that is changing slowly, especially as we get more women as doctors, especially in obstetrics and gynaecology, but most of us just, you know, you just carry on really (Nathan, surgeon).*

This potentially limited the diversity of responses that were gathered across the surgeon and nurse groups.

Fourthly, the gender distribution of the patient sample was 80 percent male, and cancer types included 40 percent of patients with prostate cancer and 40 percent with bowel cancer. While the number of males in the sample and those with prostate cancer potentially influenced the other, the distribution of gender and cancer types in the patient sample were not representative of the latest data published on new registered cancers in New Zealand (Ministry of Health, 2019).

Finally, while connections were established to include Māori participants from Otaki in the sample (to honour this community's contribution at the original hui), only one Māori patient and whānau member from Otaki were part of the sample. This could reflect the small population of Māori living in Otaki who met the inclusion criteria[9], but may also have been contributed to by my 'outsider' position, being non-Māori and not having any historical or present links to the community. While the process of engagement with the advisory group enabled the Māori community members of Otaki to be involved in the project development and findings, the number of Māori participants from Otaki could be seen as a limitation of the study's sample in regards to honouring the project's roots.

Overall, when considering the characteristics of the sample, it is important to take into account the study's methodology. Smith and Osborne (2008) argue that the goal of interpretative phenomenological analysis is not to make objective claims, rather it is to explore the richness of individuals' subjective lived experiences. As such, instead of the sample *limiting* the study findings, patients' treatment outcomes and the distribution of cancer types, gender, and ethnicity can be thought of as important contextualising variables when considering how the findings arose and the transferability of the study's findings. Future research could explore whether cancer type, treatment outcomes, gender, and ethnicity influenced the way participants reflected on their experiences of receiving and delivering bad news.

Interview process. A key consideration for the study's outcomes is the context of the interviews, as this was how the data was obtained. There were a number of interviews conducted with patients and family/whānau members together, resulting from giving participants the choice of

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[9] Through consultation with the advisory group, the criteria was expanded in an attempt to increase who was eligible to participate; see 'Otaki advisory group' in Chapter Four.

joint or independent interviews. Joint interviews had the potential to reveal a more complete picture of the experience when the patient was told bad news about their cancer. However, this could also have meant that certain topics were avoided, responses were more congruent with the view of the other person, and family members felt that the patient's account took precedence over their own. While I endeavoured to prompt for both patients' and family members' perspectives, the participants in joint interviews were not interviewed separately to know the extent to which being interviewed together impacted their responses. The interview data collected from the interviews with patients and family members, therefore, represent their shared understanding of the process.

Contribution of the Study to the Literature

The study outlined in this thesis set out to attend to several identified gaps in the current body of literature on the breaking of bad news to adult oncology patients. The first was in regards to the under-representation of family members' perspectives in the literature, which was attended to in the current study through the inclusion of family members as a participant group. The findings contribute an understanding that family members bring a different lens to the bad news encounter than that of the patient, and that they have their own support needs. By attending to family members' experiences, this study offers recommendations for practice that included the needs of family members.

The second was contributing to the understanding of the breaking bad news process in New Zealand, given the limited research in this context to date. While the study makes a significant contribution to the current corpus of breaking bad news literature based on New Zealand data, the findings represent the experiences of a small sample of patients, family/whānau members, and HCPs from a specific department within one DHB. As such, the findings must be considered within the context they arose when using the outcomes as evidence of the breaking bad news process in New Zealand. However, the majority of the findings were reflective of the international literature, suggesting that the current study's findings may have wider applicability.

The study also set out to gain a balanced perspective on the breaking bad news process by hearing the experiences of all those involved. The current study achieved this in two ways. Firstly, two different perspectives on receiving (i.e., patient and family member) and delivering (i.e., surgeon and nurse) bad news were included in the analysis. Secondly, a linked case study design was developed and implemented that enabled direct comparisons between the perspectives of various parties involved in a series of single-patient cases. The current study demonstrated that a linked case analysis can complement a group-based analysis and offers this as a possible study design for future research into processes that involve multiple parties.

Finally, this study offered a psychological lens on a medical process. The findings illustrate that there are numerous psychological aspects to the process of breaking bad news. As such, the recommendations for practice from this study reflect many of the central tenets of psychological practice: building a therapeutic relationship, working collaboratively with clients, engaging in a process of self-reflection (individually and through supervision), and attending to self-care. This study offers an example of how the field of Psychology can contribute to medical practice.

Final Words…

Breaking bad news about cancer is a difficult and complex process for everyone involved, with numerous factors to be carefully considered. There is a collective responsibility among healthcare organisations, training providers, HCP teams, and individual HCPs to make this process go as well as possible for all those involved. The significance of the process of breaking bad news, for both the receivers and deliverers, means that it deserves consideration, prioritisation, and resourcing as a key part of effective cancer care. In the words of Buckman:

> *"If the breaking of bad news is done badly, patients and their families may never forgive us, but if it is done well, they will never forget us" (Buckman, 1996, p. 669-700).*

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Appendix A: Statement of Candidate Contribution to Publications/Manuscripts

DRC 16

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate's Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of candidate:	Tamyra Matthews
Name/title of Primary Supervisor:	Dr Donald Baken
Name of Research Output and full reference:	
Publish manuscript: Matthews, T., Baken, D., Ross, K., Ogilvie, E., & Kent, L. (2019). The experience of patients and their family members when receiving bad news about cancer: A qualitative meta-synthesis. Psycho-Oncology, 28(12), 2286-2294. doi: 10.1002/pon.5241	
In which Chapter is the Manuscript /Published work:	Chapter Three, Part One
Please indicate:	
• The percentage of the manuscript/Published Work that was contributed by the candidate:	85%
and	
• Describe the contribution that the candidate has made to the Manuscript/Published Work:	
The candidate was the primary author of the meta-synthesis, leading the identification of articles, data analysis, and writing of the manuscript.	
For manuscripts intended for publication please indicate target journal:	
Candidate's Signature:	
Date:	25/02/2020
Primary Supervisor's Signature:	Don Baken Digitally signed by Don Baken Date: 2020.02.26 08:23:35 +13'00'
Date:	26/02/2020

(This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis)

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MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate’s Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate’s contribution as indicated below in the *Statement of Originality*.

Name of candidate:	Tamyra Matthews
Name/title of Primary Supervisor:	Dr Donald Baken
Name of Research Output and full reference:	
Submitted manuscript: Matthews, T., Baken, D., & Ross, K. (2019). Single cases from multiple perspectives: A qualitative study comparing the experiences of patients, patients’ family members, surgeons, and nurses when bad news is delivered about cancer. Manuscript submitted to Journal of Psychosocial Oncology, Research, and Practice.	
In which Chapter is the Manuscript /Published work:	Chapter Five, Part Two
Please indicate:	
• The percentage of the manuscript/Published Work that was contributed by the candidate:	90%
and	
• Describe the contribution that the candidate has made to the Manuscript/Published Work:	
The candidate was the primary author for this manuscript, conducting data collection, data analysis, and the writing of the manuscript.	
For manuscripts intended for publication please indicate target journal:	
Manuscript submitted to Journal of Psychosocial Oncology, Research, and Practice.	
Candidate’s Signature:	
Date:	25/02/2020
Primary Supervisor’s Signature:	Don Baken Digitally signed by Don Baken Date: 2020.02.26 08:24:59 +13'00'
Date:	26/02/2020

(This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis)

Appendix B: eMERGE Guidelines for Synthesising Qualitative Literature [Manuscript one]

No.	Criteria	Evidence
Phase 1- Selecting Meta-ethnography and getting started		
1	Rationale and context for the meta-ethnography: Describe the gap in research or knowledge to be filled by the meta-ethnography, and the wider context of the meta-ethnography	p. 22-24
2	Aim(s) of the meta-ethnography: Describe the meta-ethnography aim(s)	p. 24
3	Focus of the meta-ethnography: Describe the meta-ethnography review question(s) (or objectives)	p. 24
4	Rationale for using meta-ethnography: Explain why meta-ethnography was considered the most appropriate qualitative synthesis methodology	p. 23-24
Phase 2- Deciding what is relevant		
5	Search strategy: Describe the rationale for the literature search strategy	p. 24
6	Search process: Describe how the literature search was carried out and by whom	p. 24-25
7	Selecting primary studies: Describe the process of study selection and screening, and who was involved	p. 24-25, Appendix D
8	Outcome of study selection: Described the results of study searches and screening	p. 24-25
Phase 3- Reading included studies		
9	Reading and data extraction approach: Describe the reading and data extraction method and processes	p. 24-25
10	Presenting characteristics of included studies: Describe characteristics of included studies	Table 4, Appendix E
Phase 4- Determining how studies are related		
11	Process for determining how studies are related: Describe the methods and processes for determining how the included studies are related (which aspects of the studies were compared and how the studies were compared)	p. 27, 30
12	Outcome of relating studies: Describe how studies related to each other	p. 29-30
Phase 5- Translating studies into one another		
13	Process of translating studies: Describe the methods of translation - Describe steps taken to preserve the context and meaning of the relationships between concepts within and across studies - Describe how the reciprocal and refutational translations were conducted - Describe how potential alternative interpretations or explanations were considered in the translations	p. 27, 30
14	Outcome of translation: Describe the interpretative findings of the translation	p. 30-36
Phase 6- Synthesizing translations		
15	Synthesis process: Describe the methods used to develop overarching concepts (“synthesised translations”). Describe how potential alternative interpretations or explanations were considered in the synthesis	p. 27
16	Outcome of synthesis process: Describe the new theory, conceptual framework, model, configuration, or interpretation of data developed from the synthesis	p. 30-36
Phase 7- Expressing the synthesis		
17	Summary of findings: Summarise the main interpretative findings of the translation and synthesis and compare them to existing literature	p. 36-38
18	Strengths, limitations, and reflexivity: Reflect on and describe the strengths and limitations of the synthesis - Methodological aspects (e.g., describe how the synthesis findings were influenced by the nature of the included studies and how the meta-ethnography was conducted.	p. 38

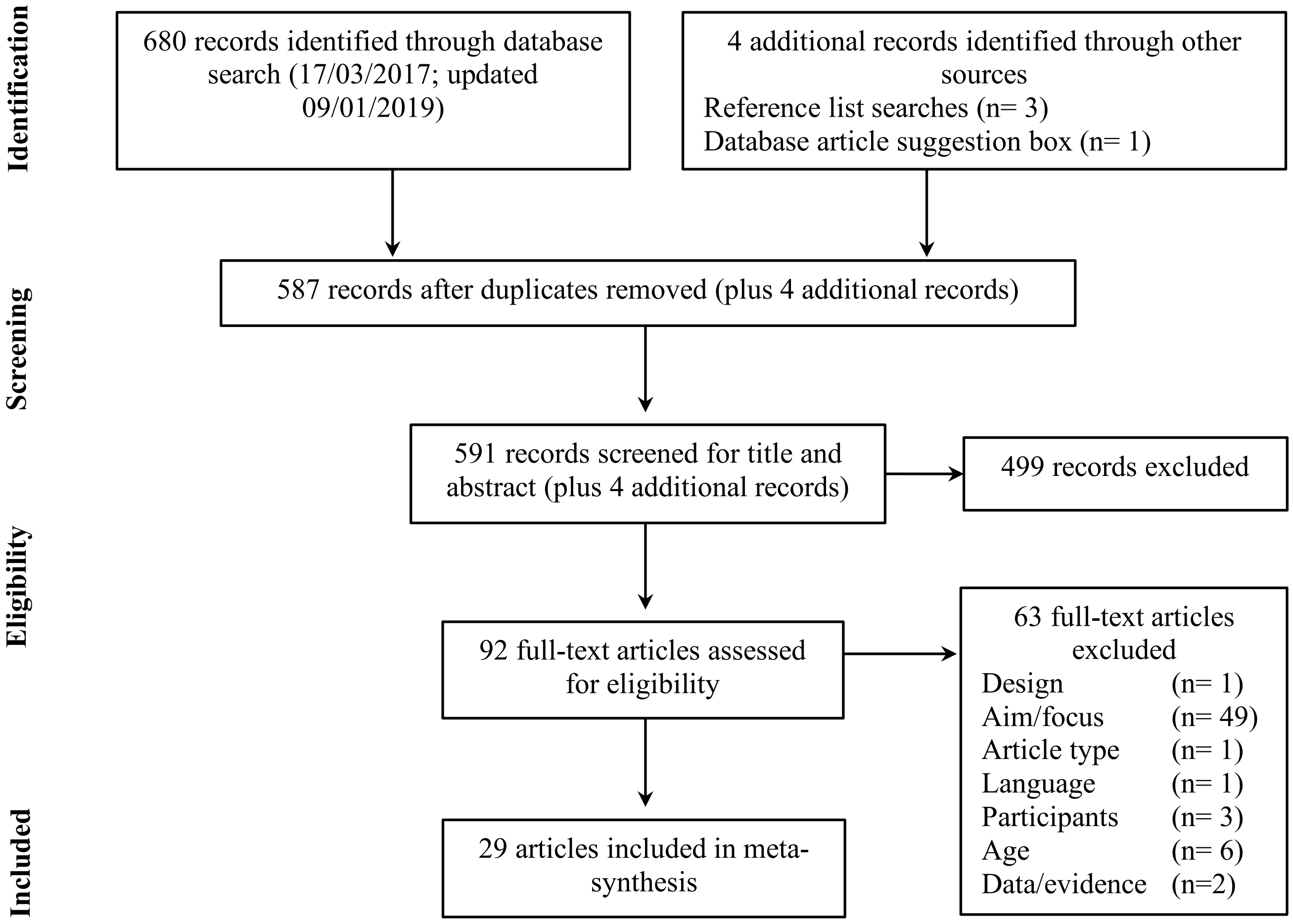
	- Reflexivity (e.g., the impact of the research team on the synthesis findings)	
19	Recommendations and conclusions: Describe the implications of the synthesis	Table 5, p.39

Appendix C: Quality Appraisal of Each Included Article in Meta-synthesis [Manuscript one]

Article code	Scope and purpose	Design	Sampling strategy	Analysis	Interpretation	Reflexivity	Ethical dimensions	Relevance and transferability
A1	Y	Y	Y	Y	P	N	Y	Y
A2	Y	P	Y	Y	Y	N	Y	Y
A3	Y	P	Y	Y	P	N	N	Y
A4	Y	P	Y	P	P	P	Y	Y
A5	Y	Y	P	Y	Y	Y	Y	P
A6	P	P	P	P	P	N	Y	Y
A7	Y	Y	P	Y	P	Y	Y	Y
A8	Y	Y	Y	Y	P	N	Y	Y
A9	Y	Y	Y	Y	Y	N	Y	Y
A10	Y	Y	Y	P	N	N	N	Y
A11	Y	Y	Y	Y	P	N	Y	P
A12	Y	P	N	P	P	N	Y	Y
A13	Y	Y	P	Y	P	N	Y	Y
A14	Y	P	Y	Y	Y	N	Y	P
A15	Y	P	N	Y	P	N	Y	P
A16	Y	P	N	Y	Y	N	Y	P
A17	P	P	N	P	N	N	Y	Y
A18	Y	P	P	Y	P	N	N	Y
A19	Y	Y	P	Y	Y	N	Y	Y
A20	Y	Y	Y	Y	P	N	Y	P
A21	Y	P	Y	Y	P	Y	Y	Y
A22	Y	Y	Y	Y	P	N	Y	Y
A23	Y	P	N	Y	Y	N	N	Y
A24	Y	P	Y	P	P	N	N	Y
A25	Y	Y	N	Y	P	N	Y	Y
A26	Y	Y	N	P	N	N	Y	P
A27	Y	Y	Y	Y	P	P	Y	P
A28	Y	P	Y	Y	P	N	Y	Y
A29	Y	Y	Y	P	N	P	Y	P

Y= Criterion met; P= Criterion partially met; N= Criterion not met

Appendix D: PRISMA Flow of Information Diagram [Manuscript one]



Appendix E: Full Details of Study Characteristics of Included Articles in Meta-synthesis [Manuscript one]

Code	Author, year	Article title	Aim/focus	Participants	Country [10]	Data collection	Methodology, sampling	Bad news type	Cancer type
A1†	Abazari et al. (2016)	Exploring perceptions and preferences of patients, families, physicians, and nurses regarding cancer disclosure: A descriptive analysis.	Explore perceptions and preferences of cancer patients, their families, physicians, and nurses in disclosing cancer diagnoses.	Sample size: 15 patients, 6 family members Age: patients (mean= 44.7, within range= 20-69); family (mean= 49.2, within range= 30-69) Sex: patient (9 female, 6 male), family (3 female, 3 male) Recruitment site: University hospital	Iran	Semi-structured interviews	Content analysis Purposive sampling	Diagnosis	Colon, haematological, breast, brain, skin, Hodgkin's disease
A2†	Blakely et al. (2017)	Optimistic honesty: Understanding surgeon and patient perspectives on hopeful communication in pancreatic cancer.	Understand the information needs and communication experiences of patients treated surgically for pancreatic cancer, and the perceived enablers and barriers to	Sample size: 10 patients, 8 family members Age: patients (mean=65.6, range= 43-82); family (over 18 years)[11] Sex: NS Recruitment site: Cancer centre	Canada	Semi-structured interviews	Grounded theory Purposive sampling	Prognosis	Pancreatic

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[10] If the country in which the study was conducted was not explicitly stated, the country reported was inferred by the location of the researchers

[11] Confirmed by emailing author

			effective communication.						
A3†	Butow et al. (2002)	Communicating prognosis to patients with metastatic disease: What do they really want to know?	Obtain patient and health professional views on optimal ways of presenting prognosis to patients with metastatic breast cancer.	Sample size: 17 patients Age: mean= 50, range= 38-80 Sex: 17 female Recruitment site: NS	Australia	Semi-structured interviews	Content analysis Constant comparative method Convenience sampling	Prognosis	Breast
A4	Chen et al. (2018)	The differences in preference for truth-telling of patients with cancer of different genders.	Explore gender differences for patients with cancer in truth-telling and preferences for decision making.	Sample size: 20 patients Age: mean= 52.2, range= 30-77 Sex: 10 female, 10 male Recruitment site: medical centres	Taiwan	Semi-structured interviews	Content analysis Purposive sampling	Diagnosis	Breast, lung, liver
A5	Chircop & Scerri (2017)	Being diagnosed with cancer: The experiences of patients with non-Hodgkin's lymphoma.	Explore the lived experience of patients on receiving a diagnosis of non-Hodgkin's lymphoma.	Sample size: 6 patients Age: range= 44-81 Sex: 2 female, 4 male Recruitment site: haematology ward, oncology centre	Malta	Semi-structured interviews (two time-points)	Interpretative phenomenological analysis Sampling method NS	Diagnosis	Non-Hodgkin's lymphoma
A6†	Deschepper et al. (2008)	Truth-telling at the end of life: A pilot study on the perspectives of patients and	Describe attitudes towards truth-telling of terminal patients and professional caregivers, and to	Sample size: 17 patients, 8 family members Age: over 18 years Sex: NS Recruitment site:	Belgium	In-depth interviews	Grounded theory Constant comparison method	Diagnosis prognosis, end-of-life	Lung, prostate, other

		professional caregivers.	determine their perceived barriers to full information exchange.	palliative care centres			Purposive sampling		
A7	Friedrichsen et al. (2011)	Experiences of truth disclosure in terminally ill cancer patients in palliative home care.	Explore the experiences and preferences of terminally ill cancer patients regarding truth-telling in the communication of poor prognosis.	Sample size: 45 patients Age: mean= 66, range= 29-84 Sex: 26 female, 19 male Recruitment site: palliative care units	Sweden	Interviews	Hermeneutic approach Sampling method NS	Prognosis	Gastrointestinal, urogenital, lung, breast, haematological, sarcoma, brain, other
A8‡	Friedrichsen et al. (2000a)	Breaking bad news in the transition from curative to palliative cancer care – Patients' view of the doctor giving the information.	Explore how patients with a disseminated cancer disease experienced the information about their transition from a curable to an incurable state.	Sample size: 30 patients Age: mean= 68, range= 29-86 Sex: 18 female, 12 male Recruitment site: palliative hospital-based home care unit	Sweden	Semi-structured interviews	Phenomenographical approach Maximum variation sampling	Transition to palliative care	Gastrointestinal, urogenital, haematological, sarcoma, other
A9‡	Friedrichsen et al. (2000b)	Cancer patients' perceptions of their participation and own resources after receiving information about discontinuation of active tumour treatment.	Explore how cancer patients in a palliative care setting perceive their own participation and resources after receiving information about discontinuing active tumour treatment.	Sample size: 30 patients Age: mean= 68, range= 29-86 Sex: 18 female, 12 male Recruitment site: hospital-based home care unit	Sweden	Semi-structured interviews	Phenomenographic method Maximum variation sampling	Ending active treatment	Gastrointestinal, urogential, haematological, sarcoma and other

A10	Friedrichsen et al. (2001)	Receiving bad news: Experiences of family members.	Explore the experiences of family members when receiving information about ending tumour treatment in patients with incurable progressive cancer, with a focus on their role in this context.	Sample size: 20 family members Age: over 18 years Sex: 9 female, 11 male Recruitment site: patients in palliative hospital-based home care	Sweden	Semi-structured interviews	Phenomenographical approach Maximum variation sampling	Ending active treatment	Patients had gastrointestinal, urogenital, brain, lung, other
A11‡	Friedrichsen et al. (2002)	Cancer patients' interpretations of verbal expressions when given information about ending cancer treatment.	Explore what significance verbal expressions had for cancer patients when they were given information about ending active tumour treatment, and what messages they felt they received.	Sample size: 30 patients Age: mean= 68 range= 29-86 Sex: 18 female, 12 male Recruitment site: palliative hospital-based home care unit	Sweden	Semi-structured interviews	Phenomenographical approach Maximum variation sampling	Ending active treatment	Gastrointestinal, urogenital, haematological, sarcoma, other
A12†	Fujimori et al. (2005)	Good communication with patients receiving bad news about cancer in Japan.	Describe attributes of good communication with patients receiving bad news about cancer in Japan.	Sample size: 42 patients Age: mean= 57, range= 31-73 Sex: 23 female, 19 male Recruitment site: outpatients	Japan	In-depth interview	Content analysis Sampling method NS	NS	Lung, gastrointestnal, breast, head and neck, haematological

A13	Furber et al. (2015)	Patients' experiences of an initial consultation in oncology: Knowing and not knowing.	Explore how patients experience an initial oncology consultation.	Sample size: 5 patient cases Age: mean= 57.6, range= 40-83 Sex: 2 female, 3 male Recruitment site: oncology outpatients	United Kingdom	Semi-structured interviews	Interpretative phenomenological analysis Maximum variation sampling (for larger study), 5 participants selected based on homogeneity of consultation type	Diagnosis and prognosis	Skin, oesophageal, head and neck, breast
A14†	Furber et al. (2013)	Investigating communication in cancer consultations: What can be learned from doctor and patient accounts of their experiences?	Investigate how doctors and patients diagnosed with advanced incurable cancer experience the disclosure of bad news.	Sample size: 16 patients Age: over 18 years Sex: 4 female, 12 male Recruitment site: oncology out-patient department at a cancer centre	United Kingdom	Semi-structured interviews	Constant comparison method Purposive sampling method	Across disease trajectory	Lung, gastric, oesophageal, pancreatic, and other
A15 †	Hanratty et al. (2012)	Breaking bad news sensitively: What is important to patients in their last year of life?	To understand patients' perspectives on how a diagnosis of a life-limiting illness was first communicated to them.	Sample size: 31 patients Age: adults[12] Sex: NS Recruitment site: NS	United Kingdom	Semi-structured interviews	Analysis based on principles of Framework Sampling method NS	Diagnosis	NS (from quotes lung, haematological, bowel)

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[12] Could not report specific age range as this information could not be separated from non-cancer patients. The age range of the overall participant group was 30-93 years.

A16	Hoff et al. (2007)	In the shadow of bad news - Views of patients with acute leukaemia, myeloma or lung cancer about information, from diagnosis to cure or death.	Investigate patients' views of information during the trajectory of their disease.	Sample size: 12 patients Age: range 37-80 Sex: 7 female, 5 male Recruitment site: university hospital	Sweden	Semi-structured interviews	Hermeneutic approach Sampling method NS	Across disease trajectory	Haematological, lung
A17	Kirk et al. (2004)	What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study.	Obtain feedback from palliative care patients and their relatives from various ethnic backgrounds about their experience of disclosure and information sharing.	Sample size: 37 patients, 35 family members (35 patient-family dyads and 2 patients) Age: over 18 years Sex: NS Recruitment site: NS	Australia and Canada	Semi-structured interviews	Latent content analysis Constant comparison method Sampling method NS	Diagnosis and prognosis	NS
A18	Lobb et al. (2011)	Patient and caregiver perceptions of communication of prognosis in high grade glioma.	Explore the views of patients and their caregivers on their experience of being diagnosed with high grade glioma.	Sample size: 19 patients, 21 family members Age: over 18 years Sex: patient (7 female, 12 male); family (17 female, 4 male) Recruitment site: medical oncology unit, tertiary hospital	Australia	Semi-structured interviews	Grounded theory Constant comparison method Purposive sampling	Diagnosis and prognosis	Brain

A19	Mardani-Hamooleh & Heidari (2017)	Psychosocial distress as a factor in patients with cancer seeking support: A hermeneutic study.	Explore the lived experiences of Iranian cancer patients when hearing bad news.	Sample size: 11 patients Age: range= 33-54 Sex: 6 female, 5 male Recruitment site: cancer wards in two teaching hospitals	Iran	Semi-structured interviews	Hermeneutic phenomenology Sampling method NS	Diagnosis	Breast, colorectal, hematologic, gynecologic, prostate
A20	Maree et al. (2014)	'Not a nice experience, not at all': Underprivileged women's experiences of being confronted with cervical cancer.	Explore the experiences of underprivileged women being confronted with a diagnosis of cervical cancer.	Sample size: 19 patients Age: mean= 47.2, range= 29-70 Sex: 19 female Recruitment site: radiation oncology department, academic hospital	South Africa	Unstructured interviews	Thematic analysis Convenience sampling	Diagnosis	Cervical
A21	Randall & Wearn (2005)	Receiving bad news: Patients with haematological cancer reflect upon their experience.	Explore the experiences of patients with haematological cancer as they reflect on the process and content of receiving bad news.	Sample size: 15 patients Age: mean= 59.4, range= 31-85 Sex: 7 female, 8 male Recruitment site: haematology outpatient clinic, day unit	United Kingdom	Semi-structured interviews	Thematic content analysis Purposive sampling	Diagnosis	Haematological
A22	Ridgway et al. (2014)	Does labelling a rare cancer diagnosis 'good' affect the patient's experience of	Explore how patients reacted to being told they have a 'good' cancer.	Sample size: 25 patients Age: over 18 years Sex: 13 female, 12 male Recruitment site: two research sites	United Kingdom	Semi-structured interviews	Thematic analysis Constant comparative analysis Purposive sampling	Diagnosis	Thyroid, larynx

		treatment and recovery?							
A23	Salander (2002)	Bad news from the patient's perspective: An analysis of the written narratives of newly diagnosed cancer patients.	Analyse how patients with recently diagnosed cancer narrate the manner in which they received their diagnosis.	Sample size: 138 patients Age: mean= 58, within range= 18-70 Sex: 93 females, 45 males Recruitment site: oncology department, university hospital	Sweden	Written accounts and 20 follow-up telephone interviews	Grounded theory Sampling method NS	Diagnosis	NS (from quotes breast, testicular, head and neck, haematological, ovarian, pituitary, brain)
A24	Schaepe (2011)	Bad news and first impressions: Patient and family caregiver accounts of learning the cancer diagnosis.	Analyse accounts of patients and their family members of learning of a cancer diagnosis.	Sample size: 28 patients, 30 family members Age: patient (mean= 44.5, range= 21-74); family (mean= 50.5, range= 27-76) Sex: patient (11 female, 17 male); family (20 female, 10 male) Recruitment site: cancer care centre	United States of America	Semi-structured interviews	Combination of grounded theory and narrative analysis Purposive sampling	Diagnosis	Haematological

A25†	Thorne et al. (2007)	Prognosticating futures and the human experience of hope.	Extend our understanding of how prognostic communications are received and interpreted by patients.	Sample size: 200 patients Age: over 18 years[13] Sex: 147 female, 53 male Recruitment site: NS	Canada	Interviews and focus groups	Secondary analysis Interpretive description Sampling NS	Prognosis	Breast, prostate, gastrointestinal, haematological, head and neck, cervix/uterus/ovary, other
A26	Thorne et al. (2010)	Helpful communications during the diagnostic period: An interpretive description of patient preferences.	Identify helpful communication during the diagnosis experience of cancer patients.	Sample size: 60 patients Age: over 18 years[14] Sex: 43 female, 17 male Recruitment site: NS	Canada	Semi-structured interviews and follow-up interviews	Interpretive description analysis Sampling method NS	Diagnosis	Breast, prostate, gastrointestinal, haematological, cervix/uterus/ovary, other
A27	Tobin & Begley (2008)	Receiving bad news: A phenomenological exploration of the lived experience of receiving a cancer diagnosis.	Explore the lived experience of receiving a cancer diagnosis.	Sample size: 10 patients Age: range= 35-60 Sex: 7 female, 3 male Recruitment site: cancer support groups, cancer society	Ireland	Unstructured interviews	Hermeneutic phenomenology Purposive sampling	Diagnosis	Breast, ovarian, colorectal, lung

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[13] Confirmed by emailing author

[14] Confirmed by emailing author

A28	Valizadeh et al. (2012)	Cancer disclosure: Experiences of Iranian cancer patients.	Explore Iranian patients' experiences of cancer diagnosis disclosure, paying particular attention to the ways of disclosure.	Sample size: 20 patients Age: mean= 47, range= 22-75 Sex: 9 female, 11 male Recruitment site: teaching hospital	Iran	Semi-structured interviews	Content analysis Purposive sampling	Diagnosis	Digestive, lung, haematological, breast, other
A29	Yardley et al. (2001)	Receiving a diagnosis of lung cancer: Patients' interpretations, perceptions and perspectives.	Document patients’ views on delivery of lung cancer diagnosis, attitudes to methods used and ideas for improvements.	Sample size: 13 patients Age: range= 58-72 Sex: 4 female, 9 male Recruitment site: medical and oncology clinics, palliative care	United Kingdom	Semi-structured interviews	Phenomenological approach Purposive sampling	Diagnosis	Lung

† Characteristics reported are of relevant participants only (i.e. cancer patient and/or family members), omitting health professionals and non-cancer patients.
‡ Same sample of patients
P= Patients, F= Family members, UK= United Kingdom, USA= United States of America, NS= Not specified

Appendix F: References of Included Articles in Meta-synthesis [Manuscript one]

A1. Abazari, P., Taleghani, F., Hematti, S., & Ehsani, M. (2016). Exploring perceptions and preferences of patients, families, physicians, and nurses regarding cancer disclosure: a descriptive qualitative study. *Supportive Care in Cancer*, *24*, 4651–4659. https://doi.org/10.1007/s00520-016-3308-x

A2. Blakely, K., Karanicolas, P. J., Wright, F. C., & Gotlib Conn, L. (2017). Optimistic honesty: Understanding surgeon and patient perspectives on hopeful communication in pancreatic cancer care. *Hepato Pancreato Biliary*, *19*, 611–619. https://doi.org/10.1016/j.hpb.2017.04.001

A3. Butow, P. N., Dowsett, S., Hagerty, R., & Tattersall, M. H. N. (2002). Communicating prognosis to patients with metastatic disease: What do they really want to know? *Supportive Care in Cancer*, *10*, 161–168. https://doi.org/10.1007/s005200100290

A4. Chen, S. Y., Wang, H. M., & Tang, W. R. (2018). The differences in preference for truth-telling of patients with cancer of different genders. *Cancer Nursing*, *41*(4), 320–326. https://doi.org/10.1097/NCC.0000000000000513

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Appendix G: Participant Information Sheets

MASSEY UNIVERSITY
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UNIVERSITY OF NEW ZEALAND

PARTICIPANT INFORMATION SHEET
Interviews with Patients and their Family/Whānau

Communicating Bad News in Health: Improving the Experiences of Patients, Patients' Family/Whānau and Health Professionals

You are invited to take part in a study looking at the experiences of patients, patients' family/whānau, doctors and nurses when bad news is told to patients during their cancer diagnosis and treatment. This information sheet is written for patients and their family/whānau, outlining what is involved in being part of this study. We hope that the results of the study will lead us to come up with a tool to help the breaking of bad news go better for everyone.

My name is Tamyra Matthews, and I am a Doctoral student in Clinical Psychology at Massey University. I am looking for patients and their family/whānau who want to share their experiences of being given bad news about cancer. At the moment, we know very little about how the breaking of bad news is for New Zealanders. What we do know is that it is a hard process for everyone, so it would be helpful to take what we learn from hearing your experiences to come up with a tool to improve the process. This project is supervised by Dr Don Baken, Dr Kirsty Ross and Ms Lizzy Kent. We have spoken with Dr Hukarere Valentine and Dr Simon Bennett for Māori cultural advice on this project. This cultural advice will continue to be given during the project.

This study will interview up to 10 patients, aged 18 years and older, who have been through a cancer diagnosis and treatment process that involved being told bad news one or more times during this journey, along with their family/whānau. In this study, family/whānau are any adults close to the patient, and they do not have to be blood relatives.

If you have any questions, please contact Tamyra on the free 0800 number listed in the contact details at the end of this information sheet. If you and your family/whānau want to take part in this study, please fill in the Interest in Participation form and send it back using the Freepost envelope that is provided. Alternatively, you can contact Tamyra on the email address or 0800 number provided at the end of this information sheet. This will allow Tamyra to get in contact with you to arrange an interview with you and your family/whānau. The Consent Forms included in this information pack will be signed at the time of the interview once any questions you have are answered. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 5 pages long. Please make sure you have read and understood all the pages.

What will my participation in this study involve?

Being part of this study will mean meeting once with Tamyra and talking about your experiences of being given bad news about cancer. If you would like to meet Tamyra and get to know her better before the interview, this can be arranged. Interviews will be done separately with patients and their family/whānau to give each person enough time to share their experiences and views, but patients and their family/whānau can be interviewed together if they would like. Our conversation could be between 30 to 60 minutes long (based on what you want to share and how much time you have) and will be sound recorded. Interviews will be held at a place that is easy for you to get to, such as at your home, or a place in the community. You are welcome to bring along a support person(s) to the interview.

The interview will cover areas such as the basic details of receiving bad news (who, what, when, where and how), what was hard, what you needed, how you felt when you heard the news, what support services you were offered or knew of, how you coped with the news and any ideas you might have that would have made the process better.

A 'linked case'

To get an 'all-round' picture of what happens when someone gets bad news, it is helpful to hear the experiences of all of those who are part of an individual patient's case (the patient, their family/whānau, and the doctors and nurses). This is what we call a 'linked case'. You will be given the option of allowing Tamyra to contact the doctors/nurses who were involved in giving bad news to you so she can hear how that process was for them. You are free to choose whether you feel comfortable with Tamyra doing this, and whether or not you agree to having a 'linked case' will not affect your ability to be interviewed.

Agreeing to have your case 'linked' to the doctors/nurses who told you bad news means:

a) Letting Tamyra know the names of the doctors/nurses who gave bad news to you.
b) Being willing for those named doctors/nurses to know that you are part of the study.
c) Tamyra getting in touch with those named doctors/nurses to see if they want to be interviewed about your specific case of giving bad news (Note: Doctors/nurses will have the choice of whether they take part and you will not be told whether or not they agreed to take part).
d) Allowing doctors/nurses to look at your medical files if needed to help them remember the specific details of your case.
e) The doctors/nurses talking with Tamyra about giving bad news to you.

While the doctors/nurses will need to be told your name so they can think about your specific case, they will not be told anything about what you have said during your interview. Additionally, anything you say that is reported in the project will not be able to identify you, as your name and any other information that might let people know who you are will be changed.

Giving your consent to having a 'linked case' will be done at the time of the interview.

Who can participate?
You can be part of the study if you are:

- 18 years or older, and
- a patient who has been through a cancer diagnosis and treatment process that included getting bad news at one or more points in time, or
- family/whānau member who was present at least once when the patient was given bad news during their cancer journey, and
- keen to talk about your experiences of receiving bad news.

What are the possible benefits and risks of this study?
Breaking bad news is hard for everyone. This study will give people a chance to have their stories heard, and for those stories to be used to come up with ideas for a tool to help the breaking of bad news go better for them, their family/whānau, and their communities, in the future.

We acknowledge that talking about being given bad news may be difficult and upsetting. To help support you and your family/whānau in times of distress, there is a list of services at the end of this information sheet that are available to you.

Who pays for this study?
There is no cost to being part of this study. As a thank you for giving your time to share your experiences, everyone will be offered a $20 supermarket voucher at the end of the interviews. Should you find it hard to get to the interview, Tamyra will arrange transport to get you there.

This study has been partially funded by Massey University Postgraduate Research Fund.

What are your rights?

- Being part of this study is your choice.
- If you do not wish to take part, you do not need to say why, and it will not affect your future health care in any way.
- If you do want to take part, but change your mind later, you can pull out of the study at any time up until one month after you have been sent the transcript of your interview to have a look over. This means your information will not be used in the study.
- You have the right to see information collected about you as part of the study (i.e. sound recordings) by getting in touch with Tamyra.
- We will get hold of you if new information gets found out during the study that may be important to your participation.
- You may wish to talk about the study with other people, such as family, whānau, friends, or health care providers before you make your decision, and we encourage you to do so.

Will my information remain private?
Tamyra and her supervisors will not know any of your contact details until you agree to be part of the study. They will not be told any of your health information other than what you choose to tell them during the interviews and what you allow them to know. Your name and

any other information that might tell people who you are will be changed in all reports of this research.

During the study, sound recordings and written copies of the interviews will be safely stored on a password protected computer that only Tamyra can use. After this, all information will be kept in a safe place at Massey University for 10 years and then destroyed.

What will happen after participating?

Once Tamyra has written up what was said in the interviews, you will be sent the transcript from your interview to look over. You will be able to cross out any information that you don't want to be part of the study and send it back to Tamyra before she starts looking at the findings. What participants say will then be used to come up with ideas for a tool to help the breaking of bad news go better for everyone. All those who are interviewed will be asked to join in focus groups to discuss and come up with these ideas. You will be encouraged to invite along anyone else who wants to join in these focus groups. Everything you need to know about being in the focus groups can be sent to you after the interviews.

You will be given the option on the Consent Form to have a summary of the main results sent to you at the end of the study.

Thank you for taking the time to read this information sheet and for your help in making this study possible.

Lead Researcher:
Tamyra Matthews
Email: [redacted]
Telephone: 0800 462 773

Contact details for more information and support

If you have any questions, or if you are unsure or unhappy about the study at any stage, you can contact:

Lead researcher
Tamyra Matthews, Doctoral student
Telephone: 0800 462 773
Email: [redacted]

Co-supervisor
Dr Kirsty Ross
Telephone: +64 (06) 356 9099 ext. 84968
Email: K.J.Ross@massey.ac.nz

Primary supervisor
Dr Don Baken
Telephone: +64 (06) 356 9099 ext. 84975
Email: D.M.Baken@massey.ac.nz

Co-supervisor
Ms Lizzy Kent
Telephone: +64 (06) 356 9099 ext. 84978
Email: L.Kent@massey.ac.nz

If you want to talk to someone who is not part of the study, you can contact a stand-alone health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Māori mental health support services, you can contact:

The Māori Health Unit/Te Whare Rapuora,
Telephone: (06) 3508210

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Help in times of distress

If you feel any distress as a result of being part of this study and would like to talk to someone about this, the following are free phone services (available 24 hours a day) that provide confidential support to anyone who is feeling emotional distress.

Samaritans	0800 726 666
Healthline	0800 611 116
Lifeline	0800 543 354
Youthline	0800 376 633

If you would like to talk to someone face to face, the www.hdc.org.nz website gives a list of mental health services in your area.

MASSEY UNIVERSITY
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PARTICIPANT INFORMATION SHEET
Interviews with Health Professionals

Communicating Bad News in Health: Improving the Experiences of Patients, Patients' Family/Whānau and Health Professionals

My name is Tamyra Matthews, and I am a Doctoral student in Clinical Psychology at Massey University. I am looking for doctors and nurses who want to share their experiences of giving bad news to patients with cancer. At the moment, we know very little about how the breaking of bad news is for people living in New Zealand. What we do know is that it can be a hard process for everyone, including health professionals, so it would be helpful to take what we learn from hearing your experiences to come up with ideas to improve the process. This project is supervised by Dr Don Baken, Dr Kirsty Ross and Ms Lizzy Kent. We have spoken with Dr Hukarere Valentine and Dr Simon Bennett for Māori cultural advice on this project. This cultural advice will continue to be given during the project.

This study will interview doctors and nurses that have given, or been involved with giving, bad news to patients with cancer.

If you want to take part in this study or have any questions, please contact Tamyra on the email address or telephone number provided at the end of this information sheet. The Consent Form will be signed at the time of the interview once any questions you have are answered. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 4 pages long. Please make sure you have read and understood all the pages.

What will my participation in this study involve?

Being part of this study will mean meeting once with Tamyra to talk about your experiences of giving bad news to patients with cancer. If you would like, you can choose to meet up with Tamyra so you can get to know each other a bit better before the interview. The interview could be between 15 to 30 minutes long (based on what you want to share and how much time you have) and will be sound recorded. Interviews will be held at a place that is easy for you to get to, such as Palmerston North Hospital. You are welcome to bring along a support person(s) to the interview.

The interview will cover areas such as the basic details of giving bad news (how, where, when, who and what), what aspects you find challenging, what support is available, what training you have received, what processes you follow, what the important considerations are, what the barriers are, and any ideas you might have that could make the process better.

Who can participate?
You can be part of the study if you are:

- a doctor or nurse who has given bad news to patients with cancer, and
- keen to talk about your experiences of giving bad news to a patient that is part of a ‘linked case’ and/or to patients with cancer in general.

A ‘linked case’
To get an ‘all-round’ picture of what happens when bad news is delivered, it is helpful to hear the experiences of all of those who are part of an individual patient’s case (the patient, their family/whānau, and the doctors and nurses). This is what we call a ‘linked case’. Patients will be given the option of consenting to have the health professionals who were involved in delivering bad news to them contacted about being interviewed about their specific case. This is so Tamyra can hear how that specific case of delivering bad news was for you.

If you are contacted to be interviewed as part of a linked case:

- You are free to choose whether or not you are willing to be interviewed about a specific patient’s case of delivering bad news.
- If you agree to be part of a linked case, you will also be able to talk more generally about your experience of delivering bad news to patients with cancer.
- If you do not want to part of a ‘linked case’, you are still able to be interviewed about your experiences of delivering bad news in general, without needing to make specific reflections on a patient’s case.

While you will be told the name of the patient who consented to having a linked case so you are able to reflect on your experience of delivering bad news to them, you will not be told what they, or their family/whānau, have said during their interview with Tamyra. Additionally, anything you say that is reported in the project will not be able to identify you, as your name and any other information that might let people know who you are will be changed.

What are the possible benefits and risks of this study?
Breaking bad news is hard for everyone, including health professionals. This study will give doctors and nurses a chance to have their perspective heard, and for this to be used to come up with ideas to help the breaking of bad news go better for health professionals, their patients and their patients’ family/whānau in the future.

We acknowledge that talking about delivering bad news may be difficult. To support you in times of distress, there is a list of services at the end of this information sheet that are available to you.

Who pays for this study?
There is no cost to being part of this study. As a thank you for giving your time to share your experiences, everyone will be offered a $20 supermarket voucher at the end of the interviews. Should you find it hard to get to the interview, Tamyra will arrange transport to get you there.

This study has been partially funded by Massey University Postgraduate Research Fund.

What are your rights?

- Being part of this study is your choice.
- If you do not wish to take part, you do not need to say why, and it will not affect your future health care in any way.
- If you do want to take part, but change your mind later, you can pull out of the study at any time up until one month after you have been sent the transcript of your interview to have a look over. This means your information will not be used in the study.
- You have the right to see information collected about you as part of the study (i.e. sound recordings) by getting in touch with Tamyra.
- We will get hold of you if new information gets found out during the study that may be important to your participation.
- You may wish to talk about the study with other people, such as family, whānau, friends, or other health care providers before you make your decision, and we encourage you to do so.

Will my information remain private?

Your name and any other information that might tell people who you are will be changed in all reports of this research. During the study, sound recordings and written copies of the interviews will be safely stored on a password protected computer that only Tamyra can use. After this, all information will be kept in a safe place at Massey University for 10 years and then destroyed.

What will happen after participating?

Once Tamyra has written up what was said in the interviews, you will be sent the transcript from your interview to look over. You will be able to cross out any information that you don't want to be part of the study and send it back to Tamyra before she starts looking at the findings. What participants say will then be used to come up with ideas to help the breaking of bad news go better for everyone. Once the findings have been written up, all those who are interviewed will be invited to join in discussion groups and come up with these ideas. You will be encouraged to invite along anyone else who wants to join in these discussion groups. Everything you need to know about being in the discussion groups can be sent to you after the interview if you are interested in taking part.

You will be given the option on the Consent Form to have a summary of the main results sent to you at the end of the study.

Thank you for taking the time to read this information sheet and for your help in making this study possible.

Lead Researcher:
Tamyra Matthews
Email: [redacted]
Telephone: 0800 462 773

Contact details for more information and support

If you have any questions, or if you are unsure or unhappy about the study at any stage, you can contact:

Lead researcher
Tamyra Matthews, Doctoral student
Telephone: 0800 462 773
Email: [redacted]

Co-supervisor
Dr Kirsty Ross
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Primary supervisor
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Co-supervisor
Ms Lizzy Kent
Telephone: +64 (06) 356 9099 ext. 84978
Email: L.Kent@massey.ac.nz

If you want to talk to someone who is not part of the study, you can contact a stand-alone health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Māori mental health support services, you can contact:

The Māori Health Unit/Te Whare Rapuora,
Telephone: (06) 3508210

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Help in times of distress
If you feel any distress as a result of being part of this study and would like to talk to someone about this, the following are free phone services (available 24 hours a day) that provide confidential support to anyone who is feeling emotional distress.

Samaritans	0800 726 666
Healthline	0800 611 116
Lifeline	0800 543 354
Youthline	0800 376 633

If you would like to talk to someone face to face, the www.hdc.org.nz website gives a list of mental health services in your area.

Appendix H: Independent Support Person Confidentiality Agreement

MASSEY UNIVERSITY
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UNIVERSITY OF NEW ZEALAND

Communicating Bad News in Health: Improving the Experiences of Patients, Patients' Family/Whānau and Health Professionals

INDEPENDENT SUPPORT PERSON CONFIDENTIALITY AGREEMENT

I .... (Full Name- printed) agree to being an independent support person during the interview.

I agree to help with the interpretation of the participant's story when required.

I agree to keep confidential all the information provided to me from the interview.

Signature: .... **Date:** ....

We appreciate your time and expertise in helping with this project.

Appendix I: Summary of Findings

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SUMMARY OF FINDINGS

Communicating Bad News in Health: Understanding the Experiences of Patients, Patients' Family/whānau and Health Professionals

In 2017 Tamyra Matthews, a doctoral student at Massey University supervised by Dr. Don Baken and Dr. Kirsty Ross, investigated breaking bad news at Palmerston North Hospital. This was a project conducted at the request of the Cancer District Group. The research involved interviewing 10 patients diagnosed with cancer, 6 family/whānau members who were present when the bad news was given, 5 surgeons and 6 senior nurses. While the thesis is not yet completed, the majority of the analysis is, and the research team felt it is important to make the findings available as soon as possible. This brief document is a summary of the key findings relating to breaking bad news. The summary is written in sections based on the interviews that were had with patients, family/whānau, surgeons and nurses.

Patients' experiences

When asked to share their cancer experience, most patients began by describing early signs that they noticed in their bodies that told them that something was not right with their health, or suspecting they might have cancer due to repeated tests. Nevertheless, hearing the news that they did have cancer understandably produced strong reactions, including shock, disbelief, anger and confusion, as patients tried to make sense of what they had been told. Some patients noticed that their reactions changed in the short space of time following hearing the news, often going from shock into "what's next" mode. Many patients felt that hearing the news in a straightforward way and then discussing possible treatment options within the same consultation helped to reduce their fear and gave them hope, knowing there were options going forward. Patients were more likely to have had a negative experience when the steps going forward were not well explained, medical words were used that were not understood by everyone in the room, and not enough information was given.

Patients reported that when there were health professionals involved that were outside of the hospital system (e.g., GP), breakdowns in communication made things harder for the patient to get the information they needed. There were many patients who experienced a waiting period to have tests done, to get test results or to go in for surgery. They often described waiting as the worst part, as their minds were filled with negative thoughts and concern about their cancer getting worse. Patients also felt let down by the hospital system when they expected better treatment than they got (e.g., surgery complications, lack of access to personal care products and home support, and insufficient follow through from patient advocacy). Some patients shared that this left them feeling discriminated against.

For many patients, an important part of feeling cared for by their medical team was getting along with their surgeon and nurses. This began for most patients when they first met their surgeon and they found common ground through sharing information about their backgrounds and interests. This building of a therapeutic alliance through making connections/whakawhanaungatanga resulted in patients feeling like they were seen by their surgeons and nurses as a 'person' rather than just a 'patient' or a 'number'. Surgeons using language that patients could understand was important, and when complicated medical words were used, some patients found this got in the way of forming a relationship. Many times patients shared stories of using humour with their surgeons and nurses and this came from getting to know them well. Some patients also mentioned how they benefitted from a good relationship with the nurses who visited them in their homes and with community support workers. Thus, the importance of relationships with health professionals was a key finding for improving confidence and trust in the medical processes, and enhancing wellbeing.

Family/whānau members' experiences

The family/whānau that were interviewed were in the room when the news of cancer was given to their loved one. When the news came unexpectedly, family members spoke about being "shocked". Some family members spoke about their reactions being influenced by them suspecting that it might be cancer and having prepared themselves for either outcome. On hearing the news, many mentioned how natural it was to take on a supporting role for their loved one. This role often involved being the patient's protector, which for some meant being present at doctor visits and advocating for the patient to get the care they needed from the hospital system and from those around them (e.g., family, friends, and the community). For many, their support role also involved being the holder of information given by the doctors and nurses, writing down notes and asking questions. It was often family members who felt that doctor visits were a bit of an "information overload".

Many of the family members recalled the news of cancer being told to them in a straightforward, "matter of fact" way, and for most, they saw no other way of doing it. However, it was important for family members that this was done in a way that made them and the patient feel they were cared for by the health professional giving the news. The kinds of things that made them feel this way was when the doctor or nurse sat down to talk to them, spoke kindly, listened carefully, was empathetic, gave extra time to answer questions, and used language that everyone in the room understood. Family member's felt a lack of caring when the health professional was seen to be dismissive of their needs or be rushing through the appointment.

Family/whānau recognised how helpful it was to get support for themselves from others during the cancer journey so they could be better supporters. Things that 'supported the supporters' was having health professionals ask about how they were doing, having wider family come on board to help out and drawing on support from their neighbours and the community. It was mentioned that having a work place that was understanding and gave them time off so they could care for their loved one was particularly helpful.

Even though receiving the news of cancer was very challenging for both the family members and patients, they expressed understanding towards the surgeons and nurses, recognising that it must be hard for them to have to tell patients bad news regularly.

Surgeons' experiences

The surgeons that were part of this study worked at Palmerston North Hospital. When talking about delivering bad news to patients about cancer, they spoke about this being a very challenging part of their job, and that the process could have an emotional impact on them. Despite this, surgeons knew that giving bad news was always going to be part of their job, and were committed to doing the best that they could, being very aware of the impact this news had on patients and whānau. Participating in this research was one way they were trying to improve how they communicated bad news, as they had not been given any formal training or instruction as to the best way to break bad news to people. Instead, learning how to do it was mostly through years of experience. Surgeons said that experience had taught them that they needed to find ways of coping with this difficult part of their work so they could keep performing this role. These coping strategies involved things such as being able to separate work from their home life.

A big part of delivering bad news for surgeons was showing care towards their patients. This sometimes was in the form of taking extra time in the consultation, changing how the news was said based in the needs of the individual patient, and providing hope. Like patients and whānau, surgeons spoke about the importance of forming a relationship with their patients, and talked about taking time to get to know their patients and their interests, being open and honest, and staying alongside the patient as they moved through their treatment. They spoke about enjoying getting to know their patients and their family/whānau, but this also meant that sometimes it was more emotional when news was not as good as they had hoped. All surgeons recognised how crucial family/whānau were when bad news was delivered. They spoke about encouraging family to come along to support the patient when news was given and to ask questions.

All the surgeons mentioned that there were factors that limited their ability to give bad news in the way they would ideally like to. These included having limited time (i.e., needing to see lots of patients in one day), and not having a quiet, private space to tell patients bad news. They would like to change these aspects of the system they worked in, but felt some elements were beyond their control. One way of managing within the current hospital system was by working as a team with the nurses. They admitted that the current process could be improved and were very interested in, and open to, hearing feedback from the study so they could better care for their patients.

Nurses' experiences

The nurses that were interviewed worked at Palmerston North Hospital and were involved in the process of giving bad news to patients, mostly working alongside surgeons. The nurses shared many of the same points that were made by the surgeons. They also found being involved in the process of giving bad news personally challenging as they viewed their patients as people and therefore empathised strongly with them. The nurses recognised that the process "never got easier" no matter how long they had worked in the field. As with surgeons, nurses spoke about needing to find ways to cope with their own emotional reactions to this part of the work, which included debriefing with colleagues and knowing when they needed to take a break. As with surgeons, caring for themselves helped them to keep caring for their patients.

The nurses spoke about clear roles that they saw surgeons and nurses taking. Surgeons were seen as the ones that delivered the news and nurses were there alongside them to provide support to the patient, give further information and check the patient's understanding of what the surgeons had said. They worked as a team in this way to provide a complete package of care. There was discussion of the possibility of nurses being the ones to deliver news to patients, as that they may have more time and may already have a relationship with the patient. When nurses got to know their patients well, they spoke about how rewarding this was for them.

As with surgeons, nurses were open about the current system having its shortcomings. A major contributor to this was the current hospital setting not being suitable for breaking bad news, having limited space and limited privacy. Improving the environment was mentioned as a definite way to improve the current way bad news was delivered. The pressure placed on the health professionals in terms of limited time and resources meant that news could not be delivered as well as they would ideally like it to be.

Within these organisational limitations, nurses felt that there were a number of things that could be done that helped the difficult process of breaking bad news to go as well as possible. All nurses mentioned how crucial family/whānau support was right from the start and throughout the cancer journey. When family support was not at hand, nurses spoke about moving into that support role for patients. Like surgeons, giving hope to patients was spoken about as key, no matter what the situation was. Nurses said they wanted to help empower their patients and whānau to make their own decisions about treatment and the pathway forward. They acknowledged that every patient's circumstances were different and so the process of delivering news needs to be changed to suit the person in front of them. Being able to "read the patient" and find out what their needs are helped them to do this, and this was made possible through knowing the patient.

From these findings, the following recommendations are made:

- Surgeons and nurses should continue to work together as a team when delivering news about cancer in order to provide a complete package of care within the current time constraints.
- Health professionals should prioritise relationship building with patients and family/whānau members early on. Additional training around building a therapeutic alliance within time constraints should be offered to staff.
- During the consultation when news is delivered, health professionals should focus on clear communication (including using language understood by everyone present), providing access to information and communicating a sense of hope going forward.
- All participants agreed that family/whānau are key in the process of being given bad news and patients should continue to be encouraged to have family/whānau present

at consultations. Health professionals should recognise the impact of bad news on the family/whānau present and lend support to them, as well as the patient.

- Sufficient time is essential to the process of communicating bad news about cancer and should be considered when organising health professionals' workloads.
- Any future building projects need to ensure that there is appropriate space allocated for bad news discussions. In this context, 'appropriate' means sound proofing and sufficient space to accommodate family/whānau.
- Consideration needs to be given to the impact this process has on surgeons and nurses and systems should be set up to support the staff who do this task.

Thank you for taking the time to read this research summary. If you have any questions, please do not hesitate to get in touch.

Ngā mihi nui/ Kind regards

Tamyra Matthews
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Massey University

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Postgraduate Suite T4
P O Box 756
Wellington, 6140

Appendix J: Interest in Participation Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Communicating Bad News in Health: Improving the Experiences of Patients, Patients' Family/Whānau and Health Professionals

INTEREST IN PARTICIPATION

If you are interested in taking part in this study, please complete this form and return it using the Freepost envelope that is provided.
I understand that filling in and returning this form will allow Tamyra to get in contact with me to arrange an interview with me and my family/whānau (if they are interested). The Consent Forms that are included in this information pack will be signed at the time of the interview once any questions I have are answered.

I ____ (patient name) and my family/whānau (cross out if they are not interested) are interested in taking part in this study.

Signature _______________________________________ Date ______________________

The best way to get hold of me is:

Telephone ☐ Contact telephone number: ______________________________

Email ☐ Contact email address: __________________________________

Letter (post) ☐ If so, please give the best address to send a letter to:

____

____

____

____

Appendix K: Participant Consent Forms

PATIENT CONSENT FORM

Interviews

Communicating Bad News in Health: Improving the Experiences of Patients, Patients' Family/Whānau and Health Professionals

I have read and I understand the Participant Information Sheet. I have had the chance to ask Tamyra questions about this study and I am happy with the information I have been given. I have been given a copy of the Participant Information Sheet and Consent Form to keep.

I understand that taking part in this study is my choice, and that I may pull out of this study at any time up until one month after I have been sent the transcript of my interview to have a look over. Participating or pulling out of the study will not affect my continuing health care.

I understand that this study involves meeting once with Tamyra and talking about my experiences of getting bad news during my cancer journey. I understand that I can also choose to meet up with Tamyra so we can get to know each other a bit better before the interview.

I understand that agreeing to have a 'linked case' is optional and providing the names of the doctors/nurses that gave bad news to me is my choice. If I do not want to, this will not affect my participation in the study or the health care I receive.

I understand that I may bring along a support person(s) to the interview and have the option of being interviewed along with my family/whānau if I wish.

I understand that if I have any cultural needs, Tamyra will seek to meet these as best she can. I am also aware that Tamyra will ask for cultural advice about any cultural information I share with her.

I understand that Tamyra and her supervisors will not be told any of my health information other than what I choose to share during the interviews. I understand that my name and any other information that might tell people who I am will be changed in all reports of this research.

I agree to have the interview with Tamyra sound recorded.

I understand that I can contact Tamyra or her supervisors if I have any questions about the study:

Tamyra Matthews (Doctoral student)
Telephone: 0800 462 773
Email: [redacted]

Dr Kirsty Ross (Co-supervisor)
Telephone: +64 (06) 356 9099 ext. 84968
Email: K.J.Ross@massey.ac.nz

Dr Don Baken (Primary supervisor)
Telephone: +64 (06) 356 9099 ext. 84975
Email: D.M.Baken@massey.ac.nz

Ms Lizzy Kent (Co-supervisor)
Telephone: +64 (06) 356 9099 ext. 84978
Email: L.Kent@massey.ac.nz

I ____ (name)

☐ Agree to be interviewed

☐ Agree to having a 'linked case'

Signature ________________________________ Date ___________________

The best way to get hold of me is:

Telephone ☐ Contact telephone number: ___________________________

Email ☐ Contact email address: ______________________________

Letter (post) ☐ If so, please give the best address to send a letter to:

____

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____

I would like a summary of the main results sent to me at the end of the study:

Yes ☐

No ☐

If you are willing to share the following <u>demographic information</u>, please specify:

Age: ____________________________

Ethnicity: _________________________

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UNIVERSITY OF NEW ZEALAND

FAMILY/WHĀNAU CONSENT FORM
Interviews

Communicating Bad News in Health: Improving the Experiences of Patients, Patients' Family/Whānau and Health Professionals

I have read and I understand the Participant Information Sheet. I have had the chance to ask Tamyra questions about this study and I am happy with the information I have been given. I have been given a copy of the Participant Information Sheet and Consent Form to keep.

I understand that taking part in this study is my choice, and that I may pull out of this study at any time up until one month after I have been sent the transcript of my interview to have a look over.

I understand that this study involves meeting once with Tamyra and talking about my experiences of my family/whānau member getting bad news during their cancer journey. I understand that I can also choose to meet up with Tamyra so we can get to know each other a bit before the interview.

I understand that I may bring along a support person(s) to the interview and that I can choose to be interviewed along with my family/whānau member who got bad news during their cancer journey.

I understand that if I have any cultural needs, Tamyra will seek to meet these as best she can. I am also aware that Tamyra will ask for cultural advice about any cultural information I share with her.

I understand that my name and any other information that might tell people who I am will be changed in all reports of this research.

I agree to have the interview with Tamyra sound recorded.

I understand that I can contact Tamyra or her supervisors if I have any questions about the study:

Tamyra Matthews (Doctoral student)
Telephone: 0800 462 773
Email: [redacted]

Dr Kirsty Ross (Co-supervisor)
Telephone: +64 (06) 356 9099 ext. 84968
Email: K.J.Ross@massey.ac.nz

Dr Don Baken (Primary supervisor)
Telephone: +64 (06) 356 9099 ext. 84975
Email: D.M.Baken@massey.ac.nz

Ms Lizzy Kent (Co-supervisor)
Telephone: +64 (06) 356 9099 ext. 84978
Email: L.Kent@massey.ac.nz

I ____ (name)

☐ Agree to be interviewed

Signature _______________________________ Date __________________

The best way to get hold of me is:

Telephone ☐ Contact telephone number: __________________________

Email ☐ Contact email address: _____________________________

Letter (post) ☐ If so, please give the best address to send a letter to:

____

____

____

____

I would like a summary of the main results sent to me at the end of the study:

Yes ☐

No ☐

If you are willing to share the following demographic information, please specify:

Age: ___________________________

Ethnicity: ________________________

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UNIVERSITY OF NEW ZEALAND

HEALTH PROFESSIONAL CONSENT FORM
Interviews

Communicating Bad News in Health: Improving the Experiences of Patients, Patients' Family/Whānau and Health Professionals

I have read and I understand the Participant Information Sheet. I have had the chance to ask Tamyra questions about this study and I am happy with the information I have been given. I have been given a copy of the Participant Information Sheet and Consent Form to keep.

I understand that taking part in this study is my choice, and that I may pull out of this study at any time up until one month after I have been sent the transcript of my interview to have a look over.

I understand that this study involves meeting once with Tamyra to discuss my experiences of giving bad news to patients during their cancer diagnoses and treatments. This may be discussing a specific case of when I delivering bad news to a patient (with the patient's consent) who has also been interviewed as part of this research (a 'linked case'), and/or discussing my experiences with delivering bad news to patients in general. I understand that I can also choose to meet up with Tamyra to get to know each other before the interview.

I understand that I may bring along a support person(s) to the interview.

I understand that if I have any cultural needs, Tamyra will seek to meet these as best she can. I am also aware that Tamyra will ask for cultural advice about any cultural information I share with her.

I understand that my name and any other potentially identifying information will be changed in all reports of this research.

I agree to have the interview with Tamyra sound recorded.

I understand that I can contact Tamyra or her supervisors if I have any questions about the study:

Tamyra Matthews (Doctoral student)
Telephone: 0800 462 773
Email: [redacted]

Dr Kirsty Ross (Co-supervisor)
Telephone: +64 (06) 356 9099 ext. 84968
Email: K.J.Ross@massey.ac.nz

Dr Don Baken (Primary supervisor)
Telephone: +64 (06) 356 9099 ext. 84975
Email: D.M.Baken@massey.ac.nz

Ms Lizzy Kent (Co-supervisor)
Telephone: +64 (06) 356 9099 ext. 84978
Email: L.Kent@massey.ac.nz

I ____ (name)

☐ Agree to be interviewed

Signature _______________________________ Date __________________

The best way to get hold of me is:

Telephone ☐ Contact telephone number: __________________________

Email ☐ Contact email address: _____________________________

Letter (post) ☐ If so, please give the best address to send a letter to:

____

____

____

____

I would like a summary of the main results sent to me at the end of the study:

Yes ☐

No ☐

If you are willing to share the following demographic information, please specify:

Age: ___________________________

Ethnicity: ________________________

Appendix L: Semi-structured Interview Schedule

Interview with a Patient

- Can you tell me about your cancer journey?
- Can you tell me about the times during your cancer journey when you received bad news?
    - This could have been when you were diagnosed, test result, prognosis
    - Where there any other times?
- When you were told bad news, how was it done?
    - Where were you?
    - When was it given?
    - Who delivered the news?
        - Who else was there?
        - What roles did each of the health professionals take?
- Were you satisfied with how the bad news was delivered to you?
    - Why/why not?
- What went well? What did not go so well?
    - What were the implications of that for yourself and family/whānau?
- How did the way the news was delivered make you feel?
- How did you cope with getting the news?
- What were your needs during the time you got given bad news?
    - Were those needs met?
- From a cultural perspective, did you feel your needs were met?
    - Please explain.
- Were you offered information or support services after you were told bad news?
    - What support did you need/wish you had?
- What role did you see your family/whānau taking when you were told bad news?
- From your experience, how could the process of being given bad news be improved?
    - How should patients be told bad news?
    - What should be said?
    - Who should be present?
    - Where should it be done?
    - Who should deliver that news?
- Now that you have identified times when bad news was given to you, if you were to give it a definition, how would you describe what bad news is?

Sum up interview

Looks like we are coming to the end of the interview

- Are there any questions or aspects that were not covered that you wish to discuss?
- Do you have any questions for me?

Interview with a Family/Whānau Member

- Can you tell me about your involvement in […………….] cancer journey?
- Can you tell me about the times when [……………….] got given bad news when you were present in the room?
  - Where there any other times?
- When [……………..] was told bad news, how was it done?
  - Where were you?
  - When was it given?
  - Who delivered the news?
    - Who else was there?
    - What roles did each of the health professionals take?
- Were you satisfied with how the bad news was delivered to [……………]?
  - Why/why not?
- What went well? What did not go so well?
  - What were the implications of that for [……………], yourself and wider family?
- How did the way the news was delivered make you feel when you were in the room?
- What role did you see yourself taking when [……………] was told bad news?
- As family/whānau, what were your needs during the time when the bad news was told?
  - Were those needs met?
- From a cultural perspective, did you feel your needs and that of your family/whānau were met?
  - Please explain.
- Were you offered information or support services after the bad news was delivered?
  - What support did you need/wish you had?
- From your experience, how could the process of being given bad news be improved?
  - How should patients be told bad news?
  - What should be said?
  - Who should be present?
  - Where should it be done?
  - How should deliver that news?
- Now that you have identified times when bad news was given, if you were to give it a definition, how would you describe what bad news is?

Sum up interview

Looks like we are coming to the end of the interview

- Are there any questions or aspects that were not covered that you wish to discuss?
- Do you have any questions for me?

Interview with a Healthcare Professional

- Can you tell me broadly about the usual processes that are followed when breaking bad news to patients in your department?
    - Setting
    - When
    - Who present
    - Steps followed (Protocols? Guidelines? Models?)
- [if applicable] As you know, I am interviewing you as part of a ‘linked case’.
    - What do you recall from that consultation when you told [name] the news of their cancer?
        - How was it done?
        - Where was it given?
        - Who was present?
    - How was it for you when you delivered the bad news to [name]?
        - What did you feel went well?
        - What might have been done better? Or circumstances that could have made it better?
- Speaking broadly again, what do you think the most important considerations are when telling bad news to a patient?
- What is the most challenging aspect of breaking bad news for you personally?
    - How do you cope with these challenges?
- What supports are available for health professionals?
- What training did you receive in breaking bad news?
    - How do you use this training?
- What phrases/words do you use when breaking bad news? What do you avoid using?
- What are the barriers to delivering bad news well?
- What role do you see the family taking when you deliver bad news?
- What role do you see the patient’s culture playing in the process?
    - What culturally responsive practices are in place?
- How could the process of delivering bad news be made better/optimised here?
- Finally, if you were to give a definition to the term ‘bad news’, what would you describe bad news as?

Sum up interview
Looks like we are coming to the end of the interview

- Are there any questions or aspects that were not covered that you wish to discuss?
- Do you have any questions for me?

Appendix M: Transcription Notation

Round brackets within the extract indicate when there is non-verbal information that accompanies participants' utterances, e.g., (laughs), (becomes tearful).

Square brackets indicate when identifiable information has been omitted for confidentiality purposes, e.g., [daughter], [town], or text has been added that was not part of the participant's speech in order for the quote makes sense to the reader.

… indicates the joining of two pieces of an extract that are related to the same idea, but do not directly following on from each other in the flow of speech.

Quotation marks within the extract indicate when participants are quoting themselves, or others, within the story they are telling.

- indicates when a participant's utterance comes to a sudden end and is immediately followed by another utterance without a pause.

Appendix N: Consolidated Criteria for Reporting Qualitative Research (COREQ) Checklist [Manuscript two]

No.	Item	Description
Domain 1: Research team and reflexivity		
Personal characteristics		
1.	Interviewer/facilitator	T Matthews
2.	Credentials	MSc
3.	Occupation	Doctoral student
4.	Gender	Female
5.	Experience and training	TM had experience conducting interviews for a Masters and was trained in the use of micro-skills within an interview context as part of training in Clinical Psychology.
Relationship with participants		
6.	Relationship established	Participants were offered the opportunity to meet TM prior to the interviews being conducted, but none took up this offer. There was time during the interview for the TM to establish rapport with participants.
7.	Participant knowledge of the interviewer	Participants were provided with an information sheet prior to consenting to participate in the study that detailed TM's current programme of study and the aim and rationale of the study.
8.	Interviewer characteristics	TM shared with participants her personal interest in the topic, the reason the locality was chosen, and her training background.
Domain 2: Study design		
Theoretical framework		
9.	Methodological orientation and theory	Phenomenology and hermeneutics
Participant selection		
10.	Sampling	Purposive
11.	Method of approach	Patients and caregivers were recruited through hospital- and community-based healthcare workers via post and telephone. Surgeons and nurses were recruited via email.
12.	Sample size	13
13.	Non-participation	No participants dropped out of the study once they had consented to participate. However, two patients who consented to a linked case were not include in the study as they either had no caregivers present when they were told bad news or no caregivers that agreed to participate, and none of the healthcare professionals involved in their care responded to the invitation to participate. There were five surgeons identified by patients to be contacted as part of a linked case who did not respond to the invitation to participate.
Setting		

14.	Setting of data collection	Interviews with patients and their caregivers were conducted in their homes. Interviews with healthcare professionals were conducted in their place of work.
15.	Presence of non-participants	All individuals present at the interviews were participants in the study; however, participants were offered the option of bringing support person(s) along. The researcher conducted all interviews independently.
16.	Description of sample	The sample consisted of five patients, four caregivers, two surgeons, and two nurses. Patients were three males and two females, had a mean age of 60.2 years (range= 33-80), identified as New Zealand European (n=4) and European/Māori (n=1), and had diagnoses of prostate (n=2), bowel (n=2), and breast (n=1) cancers. Caregivers were one male and three females, had a mean age of 55.3 years (range= 44-69), identified as New Zealand European (n=4), and were patients' spouses/partners (n= 3) and children (n=1). The surgeons were both male and identified as New Zealand European (n=1) and European (n=1). The nurses were both female and identified as New Zealand European (n=1) and European (n=1).
Data collection		
17.	Interview guide	Participants were offered a summary of the topics that would be covered in the interviews prior to consenting to participate. The semi-structured interview schedule was reviewed by the co-authors (DB and KR) and by the Health and Disability Ethics Committee.
18.	Repeat interviews	No
19.	Audio/visual recording	The interviews were audio recorded.
20.	Field notes	No
21.	Duration	30-80 minutes
22.	Data saturation	No
23.	Transcripts returned	Participants were sent their transcripts for review and given the opportunity to add or omit any information they desired.
Domain 3: Analysis and findings		
Data analysis		
24.	Number of data coders	One; TM. The themes and supporting quotes were reviewed by DB and KR to ensure that the findings were grounded in the data.
25.	Description of the coding tree	Yes; see Figure 4.
26.	Derivation of themes	Themes were derived from the data.
27.	Software	Software was not used to manage the data.
28.	Participant checking	No
Reporting		
29.	Quotations presented	Participant quotations were presented to illustrate the themes and identified by the participant group (i.e., patient, caregiver, surgeon, or nurse) and the linked case code (see Figure 3 in the main text of the article).

30.	Data and findings consistent	The data presented was in the form of direct quotations from participants and these were consistent with, and used to support, the themes identified.
31.	Clarity of major themes	Major themes were labelled as superordinate themes in the article. These were ‘accurately perceiving and responding to needs’ and ‘carers fulfilling necessary roles’.
32.	Clarity of minor themes	Minor themes were discussed in detail in the article and were labelled as subordinate themes. These were ‘noticing and meeting emotional needs’ and ‘reading different informational needs’ under the superordinate theme of ‘accurately perceiving and responding to needs’; and ‘HCPs as providers of connection and information’ and ‘caregivers as able and willing to meet needs’ under the superordinate theme of ‘carers fulfilling necessary roles’. Each minor theme included evidence from at least two different linked cases to illustrate the diversity of the minor themes across the linked cases. Figure 4 illustrates the coding tree for the superordinate and subordinate themes.

Appendix O: Research Case Study

RESEARCH CASE STUDY

Processes of Engagement: How my Doctoral Research Experience Contributed to my Clinical Practice at Te Whare Marie

Tamyra M. Matthews

Massey University DClinPsych Candidate

Student ID: [redacted]

Clinical Psychology Intern with Mental Health, Addictions & Intellectual Disability Services

3DHB

This case study represents the work of Tamyra Matthews during her research from 2016 to 2017 and reflections as an Intern Psychologist in 2018.

Abstract

The current case study outlines the lessons from my doctoral research as applied to my mahi (*work*) as an Intern Psychologist at Te Whare Marie working with children, adolescents and whānau (*family*). This case study opens with me identifying myself as pākehā (*of European descent*) and an immigrant to New Zealand and sharing my whakapapa (*genealogy*). I provide a summary of my doctoral research and the process of engaging with a local Māori community and key stakeholder in my research project. Reflections then follow on how my research experience contributed to my development as a practitioner working with tangata whaiora (*service user*) and whānau within a kaupapa Māori Mental Health service. These reflections include being non-Māori working with Māori, exploring my own identity, the value of cultural consultation, following traditional processes of engagement, and viewing those with lived experience as the experts.

Keywords: Self-reflection; engagement; tikanga Māori; tangata whaiora; whānau

Pepeha

Tēnā koutou katoa.

Ko Umlindi toku maunga, Ko Breede toku awa.

I te taha o toku Pāpā. Ko John Matthews toku Koro. Ko Tinks Matthews toku Kuia.

No Umzantsi Afrika arā Te Tonga o Awherika rāua. Ko Tim Matthews toku Pāpā.

I te taha o toku Māmā. Ko John Gibbon toku Koro. Ko Disa Gibbon toku Kuia.

No Umzantsi Afrika rāua. Ko Cari Matthews toku Māmā.

Ko Sarah Firman toku Tuakana. Ko Ben Matthews taku Tungāne.

Ko Tamyra Matthews toku ingoa.

I whānau ahau ki Umzantsi Afrika. I tipu ake ahau ki Whakaoriori.

E noho ana ahau ki Te Whanganui a Tara ināianei.

He kaimatai hinengaro tauira ahau. No Te Kunenga Ki Purehuroa.

No reira. Tēnā koutou, tēnā koutou, tēnā koutou katoa.

My name is Tamyra Matthews. I am Pākehā and was born in Cape Town, South Africa. I moved to Masterton, New Zealand, with my immediate family when I was a child. The mountain that holds significance for me is *Umlindi*, which is the Xhosa[15] name for Table Mountain in Cape Town. The river that I relate to is the Breede River, which is near the small town of McGregor where I spent most of my childhood in South Africa. My grandparents on my mother and father's side are South African, with predominantly English heritage. I have a younger brother and an older sister. I am currently a Clinical Psychology student studying at Massey University in Wellington.

I have had the privilege of engaging with Māori whānau as part of my research and internship placement at Te Whare Marie. As this case study will demonstrate, my experience of this has significantly contributed to the on-going process of filling my kete (*basket*) with knowledge of tikanga Māori. Subsequently, this journey has facilitated a deeper understanding of my own identity and whakapapa and the importance of communicating this when engaging

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[15] Xhosa is an official language of South Africa spoken by my father.

with Māori. It is for this reason that I have opened this case study with my pepeha (*introduction of identity and heritage*).

Doctoral Research Overview

The topic of my doctoral research focused on the experiences of those involved in the breaking of bad news about cancer, namely the patients and family/whānau who receive the news, and health professionals who deliver it. This overview includes a description of the background of the project, rationale, aims, and methodology. More specific detail is then provided about the process of engagement with the Māori community of Otaki that took place as the project was being established and the plan going forward as the research progresses. The experience of engagement provided the foundation of learning that I will subsequently reflect on in my role as an Intern Psychologist working at Te Whare Marie.

Study Beginnings

In October 2014, a hui (*meeting*) was held at Raukawa Marae in Otaki called Ngā whānau i pāngia e te mate pukupuku- Whānau Lives Touched by Cancer, attended by patients, whānau, and health professionals from the surrounding region. The purpose of the hui was to hear people's experiences of the cancer and palliative care services that are currently in operation. A main theme that emerged during this hui was the challenges inherent in the process of breaking bad news within the context of cancer and palliative care. In particular, it was identified that family/whānau play a significant role throughout the process of giving bad news, and that this has been under-recognised.

Also present at the hui were members of the Cancer District Group (CDG) from MidCentral District Health Board (MDHB), who identified a need for research to be conducted on the process of breaking bad news within the surgical departments at Palmerston North Hospital. It was through the CDG, which included Otaki community members present at the 2014 hui, that the project idea was brought to Massey University and the opportunity was presented for me to be involved.

Study Rationale and Aim

‘Bad news’ has been defined as “information that results in a cognitive, behavioural, or emotional deficit in the person receiving the news that persists for some time after the news is received” (Ptacek & Eberhardt, 1996, p. 496). From an initial literature search, it was evident that breaking bad news involves many different parties: patients, their families, doctors and nurses, and is often difficult for all those involved. For patients and their relatives, receiving bad news is, understandably, a highly emotional process that may include reactions such as shock, sadness, anger, disbelief and denial (Fallowfield & Jenkins, 2004). There is evidence that the quality of how bad news is delivered has an impact on those receiving the news, such as influencing psychosocial adjustment, coping, healthcare outcomes, satisfaction with care, level of uncertainty, and anxiety and depression (Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005; Schofield et al., 2003). Literature also suggests that health professionals experience notable distress related to giving bad news. Health professionals report having difficulty processing their emotions related to delivering bad news, such as grief, sadness, frustration, anxiety and guilt (Martin et al., 2015), and there is little evidence to suggest that this diminishes with experience (Fallowfield & Jenkins, 2004).

The current and expanding corpus of literature on breaking bad news to cancer patients points to it as a topic of international relevance. There are, however, a number of gaps that provide opportunities for further research. Firstly, there is limited research on breaking bad news in the New Zealand context, particularly qualitative research on the experiences of those who have been through the process of delivering and receiving bad news. Given New Zealand’s unique bicultural context, it is insufficient to assume that international findings and guidelines will apply to those living in New Zealand. For example, the widely applied SPIKES model (Baile et al., 2000) for guiding the delivery of bad news does not explicitly acknowledge family in the process. As whānau are central within Māori culture, this brings into question the model’s applicability in New Zealand.

Secondly, as outlined previously, breaking bad news is a process that involves many different parties. However, there seems to be an imbalance in the literature, with relatively fewer studies exploring the perspectives of family members when bad news is given. This aligns with the outcome of the Otaki hui highlighting a lack of recognition for the role of family/whānau in the process.

The aim of the research was to explore the experiences of New Zealand patients (Māori and non-Māori), patients' family/whānau and health professionals (surgeons and nurses) when bad news was given to patients about cancer within services provided by MDHB. This project was designed to contribute knowledge to the consumers and providers of care at MDHB, locally, and breaking bad news literature, internationally.

Methodology

A qualitative approach was taken to address the study aim through data generated by conducting semi-structured interviews. Given the study's focus on people's lived experience of delivering and receiving bad news about cancer, interpretative phenomenological analysis (IPA) was used to analyse the data.

Participants. Participants were ten patients, six family/whānau members, five surgeons and six nurses. Patients were able to participate in the study if they were over 18-years-old, had received news that they had cancer, had a surgical procedure related to their cancer at Palmerston North Hospital and were in the follow-up stage of their treatment. Patients were able to participate regardless of their surgical treatment outcome. Family/whānau members could participate if they were over 18-years-old and were present at one or more occasions when their family member was given bad news. Family/whānau could be anyone close to the patient, not necessarily a blood relative. Surgeons and nurses were included if they worked for MDHB and delivered bad news about cancer to patients.

Procedure. The first phase of the study was to establish interest from hospital- and community-based workers in being involved in the study recruitment. Those who agreed to be involved formed the recruitment channels through which patients and their family/whānau were able to join the study. They expressed their interest in participating by contacting the researcher. A location and time for a face-to-face semi-structured interview was arranged. The majority of participants chose to be interviewed in their homes and were invited to bring along a support person(s) if they wished. Consent to participate was signed prior to starting interviews and once any questions had been answered. Participants were also given the option to consent to the health professionals who were involved in delivering bad news to them to be invited for interviewing as a ‘linked case’. Health professionals were able to decline this invitation. Interviews with patient and their family/whānau lasted approximately 30-80 minutes and were audio recorded.

Recruitment of health professionals for interviews was two-fold. Firstly, the named health professionals as part of a ‘linked case’ were contacted and provided with information about the study. Secondly, information about the study was distributed to health professionals in the involved departments to gain a wider inclusion of health professionals in the study. Health professionals that were interested in participating made contact with the primary researcher. A date and time was arranged for interviews, with all being conducted within the health professionals’ place of work. Interviews lasted 30-60 minutes and were audio recorded.

Audio recordings were transferred to computer software and typed verbatim. Transcripts were sent back to participants to review and amendments were made where requested.

Data analysis. Undertaking IPA involves an interactive process between participants’ expressions of their experiences and the researcher’s ability to reflect, understand and analyse what is communicated. This is referred to as the double hermeneutic, whereby the participant is trying to make sense of their experience and the researcher is trying to make sense of the participant’s sense-making (Smith & Osborne, 2008). IPA began by repeated and close readings of the interview transcripts. The transcripts were then individually analysed for themes that reflected the subjective experience of each participant. To ascertain collective themes, data was first looked at for those that received bad news and those that delivered it, and secondly, for themes that represented the experiences of all those interviewed. Themes were arranged into superordinate and subordinate themes (Smith & Osborne, 2008).

Ethics. The study received ethical approval from the Health and Disability Ethics Committee (reference number: 16/NTB/164) and the MDHB Māori Review of Research panel.

All participants were fully informed prior to consenting and were able to withdraw consent up to one month after receiving their transcript to review. No health information was shared with the researcher at any stage other than that which participants chose to disclose. Pseudonyms were assigned and identifying information was removed from the interview transcripts. All data remains securely stored and will be destroyed after 10 years.

When engaging with participants, an opportunity was made for whakawhanaungatanga (*establishing relationships*), karakia (*prayer*) and the sharing of kai (*food*). The establishment of an advisory group of Otaki whānau and cultural supervision through Massey University enabled Māori to be involved in the project development. These groups will be consulted in regards to the project outcome once the analysis is completed. As a sign of appreciation towards all participants for sharing their experiences, a koha was offered and findings will be presented back to interested community and professional groups for collaborative discussion and feedback.

Process of Engagement

The genesis of the project was within the Otaki community, including those who organised the hui and those who shared their stories on that occasion. Honouring the roots of the project meant that the Māori community of Otaki became a key stakeholder in the research project. There were a number of factors that required careful navigation in order to establish a link with the community. Particularly salient was myself being a non-Māori researcher looking to include the voice of Māori in my project. Additionally, I was unfamiliar with the Otaki community as a whole, having no personal history there. Detailed below is the process I followed when engaging with the Otaki community. The intention here is not to present an exemplary process, but rather one that involved learning, growth and development along the way[16].

The process began with consultation with my research and Māori cultural supervisors to discuss the best way to initiate contact with community members who attended the hui. I was

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[16] I welcome your feedback on this process.

not present at the 2014 hui and so was unknown to the leaders and whānau who participated. My primary supervisor facilitated email contact with one of the community leaders and a hui was organised near Raukawa marae in Otaki. My primary supervisor and I attended along with a number of Otaki community members who were involved in health and cancer care. The hui involved karakia to open and close, whakawhanaungatanga and the sharing of kai. This hui was held during the early stages of project development and the hope was to form connections and communicate the research ideas to establish if there was interest from the community in being involved. I was pleased that there was interest from the group and a helpful discussion was had of ways that the research project could include Otaki whānau.

Email contact followed and a number of face-to-face meetings were had with the main representative for Otaki whānau in the project. Through this, it was identified that there needed to be a formalised process of consultation developed if the voice of the Māori community were to be included in the project development, research and outcomes. I took this to cultural supervision and the suggestion was made to establish an advisory group as part of the research methodology. I had a very generous response from the community and an advisory group of four community leaders was established. The advisory group and I met to discuss the project. Feedback from the advisory group was invaluable and resulted in a number of key changes to the methodology to enable Otaki whānau to be better included in the study. These changes came about by a process of negotiation between my research and Māori cultural supervisors and the advisory group until agreement was reached. These negotiations would have ideally been in person; however, due to geographical distance and busy schedules, these negotiations were carried out over a period of time and predominantly via email.

The chance to korero (*speak*) in person came with an invitation to present the updated research proposal for wider community feedback at the follow-up hui to the 2014 hui. A mihi whakatau (*welcome*) process was followed, during which I shared my pepeha. Following the mihi whakatau process was important to acknowledge and respect differences amongst those in the room before a working relationship could be established. This was crucial to the process of engagement and the conclusion of the hui was that discussions could now begin about recruiting Otaki whānau for interviews.

In total, the process of engagement described spanned over a year and only represents the beginning of my involvement with the Otaki community. Since then, contact has been made to update the advisory group on research progress and there will be future hui offered to the community to share the findings of the project and receive feedback.

Clinical Psychology Internship

My internship began in January 2018 within the three District Health Boards (Capital and Coast, Hutt Valley, and Wairarapa). The internship consisted of two six-month placements, firstly with Te Whare Marie in the Te Kakano o Te Aroha (child and adolescent) team, and secondly with the Central Region Eating Disorder Service. The following reflections were made during my time at Te Whare Marie when engaging with tangata whaiora and whānau. They include reflections on being non-Māori working with Māori, exploring my own identity, the value of cultural consultation, following traditional processes of engagement, and viewing those with lived experience as the experts.

Non-Māori within a Māori World

My pepeha at the start of this case study identifies me as pākehā. As I sat down to write this reflection, I was struck by a familiar concern that I had felt before embarking on my engagement with Otaki whānau and my placement at Te Whare Marie: Is it appropriate for me, as a non-Māori researcher and clinician, to move into this position? Can I make a difference or contribution that is meaningful to Māori? Would my good intentions to contribute to and involve Māori in my work inadvertently perpetuate the disservice that Māori have historically faced at the hands of pākehā in a research and clinical space? Would I say or do something out of ignorance that would be unkind or cause offence? These questions were always at the forefront of my mind during times of engagement and were a source of anxiety for me.

Being given the opportunity to work with Māori in my research and clinical practice, I had to think carefully about how I was going to approach this as pākehā. Beginning during my research and extending to my time at Te Whare Marie, I decided to adopt a stance of openness. This involved opening my mind to learning different ways of being in the world, opening my eyes and ears to the richness of knowledge present in cultural practices, opening myself up to feedback and growing from mistakes, and opening my heart to embrace tikanga Māori. Some aspects of this were easier than others. For example, it was highly rewarding to 'jump in the waka (*canoe*)' with cultural practices such as waiata (*song*) and karakia. More challenging for me was realising that I might get things wrong, when I so badly wanted to get them right. Actively seeking feedback from my cultural supervisors and the Otaki advisory group, I believe, prepared me well for managing feedback in my intern role in a context where I had a lot to learn clinically and culturally.

Exploring my own Identity

One of the most salient lessons I learnt about being non-Māori when engaging with Māori was the importance of knowing my own cultural identity. I remember feeling a strong sense of apprehension ahead of a hui with the Otaki community when I was going to share my pepeha as part of the whakawhanaungatanga process. I had spent much time reflecting individually and with my family on what was important to me, and what it meant to me to be South African born and an immigrant to New Zealand. I was exposing myself and I feared rejection based on my background. I was pleasantly surprised when the opposite occurred; sharing my whakapapa seemed to help facilitate connection with the Otaki community. This was directly transferable to my work at Te Whare Marie, where sharing some information about your whakapapa is an important part of developing rapport with tangata whaiora and whānau. The degree of self-disclosure within a kaupapa Māori context differs from a European context of which I am most familiar, so I was thankful that I had the experience of the Otaki community's positive reaction to my pepeha to give me confidence that sharing my background would be a vehicle in relationship building with Māori.

Cultural Consultation

Prior to my doctoral research, I had not had experienced taking a lead role in engaging with Māori community groups, and moving into this role required cultural guidance. It is both my ethical responsibility and practically necessary for me, as pākehā, to consult on aspects related to Māori tikanga (*customs, protocols*). My experience of consultation with my university-based cultural supervisors and the Otaki advisory group highlighted to me why this process is so important. In both instances, cultural consultation lead to important changes in the research process that would not have occurred otherwise, namely the development of the Otaki advisory group and altering the inclusion criteria of my study to be more inclusive of Otaki whānau. I was very grateful for having this guidance.

On arriving at Te Whare Marie, I was ready to prioritise cultural consultation in my work. I was fortunate to have input from kaumatua (*male elder*), kuia (*female elder*), a cultural therapist, and Māori kaimahi (*staff*) in an informal and multidisciplinary team setting. One pertinent example of the benefit of cultural consultation was when a treatment plan was altered to include a cultural intervention alongside the Cognitive-Behavioural Therapy work I was doing with a young person experiencing post-traumatic stress disorder and wairua distress. I recognised the limitations of my competence to manage the cultural aspects of this case and sought guidance. I was able to observe that this collaborative approach was instrumental in moving this tangata whaiora towards a holistic sense of wellness that I would not have been able to achieve without cultural input.

Traditional Processes of Engagement

A parallel between my engagement with Otaki whānau for my research and tangata whaiora at Te Whare Marie was the use of traditional processes, such as mihi whakatau and hui. My research experience demonstrated to me how fundamental these traditional processes are to facilitating a working relationship between two parties that start off as unknown to one another. Having experienced the benefits personally prior to my internship, it made sense to me that Te Whare Marie used the same processes when a whānau came to meet a clinician at the service for the first time. My research experience also provided me with some familiarity and confidence when including karakia, whakawhanaungatanga and korero from all whānau members within a session.

Additionally, a key lesson I took from my research into my clinical role was shifting my orientation from being time-focussed to being process-driven. In our clinical training, we are taught that sessions are typically 50-minutes to an hour long, with evidence-based treatment guidelines often providing a recommended number of sessions (e.g., Leahy, Holland, & McGinn, 2012). However, as engagement with Māori is based on following correct process rather than a prescribed time frame, it was important to be flexible to allow sessions to go for longer, particularly in the early stages of engagement. My experience was that taking the time initially to get the process of engagement correct helped to save time later on when it came to treatment, as there was a trusting relationship with the whānau. The process of getting to know a whānau was also incredibly rewarding for me as a clinician.

Those with Lived Experience as Experts

The methodology of my doctoral research is built on the premise that those with lived experience are the holders of knowledge: the experts. This extended to my consultation with the Otaki advisory group, where the members had lived experience in the Otaki community and the needs of the whānau located there. As such, I looked to the advisory group as the experts on how I could best engage with the community. I found that when I moved into a clinical role, positioning tangata whaiora and whānau as the experts came naturally to me. My stance on this is well captured in the following article extract:

"I believe an appropriate position for non-Māori to take in this process should be to seek a position that is unknowing rather than expert, responsive rather than controlling, and one that involves more listening than talking" (Glynn, 2008 p. 22).

When I was working with adolescents and young adults during my internship placement, a way that I could uphold this was exploring their strengths (and that of their whānau) and using these to help them problem-solve the challenges they face. However, I noticed working in this way with younger children required more creativity. For example, when working with an 8-year-old who spoke fluent te reo, her expert position came from us including her teaching me te reo words and waiata as part of our sessions. It was clear that her self-confidence grew when she could take the expert role, and came with the bonus of expanding my knowledge of te reo.

In Summary

I believe that my experience of the engagement with Otaki whānau as part of my doctoral research was invaluable in providing a foundation for engaging with tangata whaiora and whānau as an Intern Psychologist. At the end of my time at Te Whare Marie I was gifted a taonga (*treasure*): a pounamu (*greenstone*) shaped as a heart with a koru carved inside. I was told that it represented growth within someone's heart. This felt very apt as through my engagement with Māori whānau across my research and clinical practice, I can truly say that I am different from when I started. And this is something that I can feel in my heart.

Writing this case study required me to spend many hours reflecting on the lessons I learnt in my research and internship with Te Whare Marie. The more I did so, the more I realised how important it was for me to acknowledge the gift that this was. I have much more to learn, but I will take each lesson with me into my future practice. For this reason, I will close with the following whakatauki (*proverb*):

Titiro whakamuri, kokiri whakamua.

Look back and reflect so you can move forward.

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